Aspects of joint protection education in people with rheumatoid arthritis

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Content

Chapter 1
Introduction

Rheumatoid arthritis

Musculoskeletal disorders are the most common cause of chronic disorders. They have a major impact on work capacity, the health care system and the health insurance system, and, not least, on the affected individual's quality of life (1). Rheumatoid Arthritis (RA) is a chronic, systemic disease with both short and long-term impact. Prevalence is 0.8-1% and mostly RA affects people of working age. Thus, despite the relatively low prevalence rate, the economic consequences of the disease are considerable (2, 3). The course of the disease is unpredictable; it may be intermittent, but is generally progressive. Disease activity is associated with painful inflammation, which may lead to joint destruction and deformity and functional loss (4).

Management of rheumatoid arthritis

Medical drug treatment is the cornerstone and includes early treatment, tight control, drug combinations and the introduction of biologicals, such as anti-TNF and Rituximab treatment, however a comprehensive multidisciplinary approach is state-of-the art for the management of people with rheumatoid arthritis (RA) (5). Generally this active treatment strategy is efficient, in terms of disease control and the long-term perspectives of achieving complete remission and preventing progressive radiographic joint damage has become a realistic aim (6, 7). However, not all patients take all advantages of modern drug treatment. In consequence, non-pharmacological interventions are still important, especially for patients who continue to experience relevant impact of the disease, in terms of physical impairments including pain, reduced joint mobility and muscle function, or symptoms such as impaired sleep and energy function (8), possibly associated with depression and anxiety (9, 10). This may impose a number of limitations and restrictions on patients' daily activities, but also on their relationships (family, friends, work participation (remunerative and non-remunerative) and engagement in leisure time and social activities. All of these may seriously affect quality of life (8). Physiotherapy and occupational therapy aim to maintain or improve functional abilities and thus independence and quality of life (11, 12). Moreover, aims and contents have shifted as a consequence of the much more effective drug treatment. Modern physiotherapy also focuses on restoring and keeping a physically active lifestyle, including counselling on sports activities (13) whereas occupational therapy increasingly pays also attention to (individually) meaningful, rather than just purposeful occupations in everyday activities and social roles (14).

Rheumatoid arthritis patient education

Complementary to these 'traditional' therapeutic interventions, RA patient education has become an established approach, enabling patients to play an active role in the management of their disease and improve coping with the disease (15, 16). For this,

patients need a range of competencies that have been defined in the standards for arthritis patient education (17):

Patient education is planned, organized learning experiences designed to facilitate voluntary adoption of behaviours or beliefs conducive to health. It is a set of planned educational activities that are separate from clinical patient care. The activities of a patient education program must be designed to attain goals the patient has participated in formulating. The primary focus of these activities includes acquisition of information, skills, beliefs and attitudes which impact on health status, quality of life, and possibly health care utilization.

Thus, a multitude of interventions have been developed. There are educational programs focusing on information given by means of more traditional teaching methods, where psycho-educational programs include concepts and techniques to enhance behavioural change. Long-term maintenance of treatment gains is of special interest for patients with chronic diseases such as RA.

In **Chapter 2**, a systematic review performed to establish the evidence of patient education in people with RA is presented. We paid special attention to the methodological quality of the studies included and to the distinction between short-and long-term effectiveness of RA patient education.

Occupational therapy in rheumatoid arthritis

People with RA are usually referred to occupational therapy when there are problems in the areas of *self-care* (e.g. dressing, mobility), *productivity* (remunerative and non-remunerative work, household, school) and *leisure* (social and recreational activities) (11). A comprehensive occupational therapy assessment identifies their functional problems and relates them to an individual's relevant activities and participation in all aspects of his/her social life (14). RA occupational therapy encompasses training of motor function and skills, instruction on joint protection (JP), counselling, advice and instruction in using assistive devices and provision of splints (18). Within these interventions, adjusting routines, problem-solving strategies and modification of the physical environment of the patient are strategies to cope with the illness, thus aiming to maintain or improve independence and social participation.

Joint Protection in rheumatoid arthritis

Development and current concept of joint protection

JP is an important concept underlying all rehabilitation of persons whose joints are at risk from arthritis (19). The development of JP principles by Joy Cordery was based on anatomy and physiology of joints and on biomechanical analysis (20). Smith et al (21) proposed that the force of normal muscular activity acting on diseased joint restraints was an important factor in the development of rheumatoid hand deformity and that deformities occur dynamically and not solely because of the disease. The pull of the

flexor tendons was identified as primary deforming force for MCP ulnar drift and volar subluxation, with subsequent ulnar dislocation of the extensor tendons. Deformity was considered as a new dynamic equilibrium following capsulo-ligamentous elongation and tendons shifts. Such a deformity could not be restored by any conservative treatment, which thus had to be preventive and consider everyday use of joints. In consequence, the JP approach aimed to reduce forces applied to the joints, i.e. that forces were no greater than the joints used could absorb. JP theory stated that reducing load and effort when performing everyday tasks would lead to reduced local inflammation activation and less pain and thus help to preserve joint structures and contribute in the longer term to reduced deformities.

Cordery formulated ten JP principles that include: 1) maintain muscle strength; 2) maintain joint range of motion; 3) avoid positions of deformity; 4) use strongest joints available for the job; 5) use each joint in its most stable anatomical and/or functional plane; 6) ensure correct patterns of movement; 7) do not hold joints or use muscles in one position for any undue length of time; 8) do not attempt activities that can't be stopped; 9) balance rest and activity; 10) respect pain. Different JP methods integrate these principles and include altering working methods e.g. working bilaterally; energy conservation (balancing activity and rest), ergonomic adaptations and use of assistive devices. These principles are to be applied in the active phase of disease or where joint instability is present (20, 22).

Cordery was aware already in 1965 that learning the methods to apply the principles in daily activities meant changing habits, and that this would be a difficult task, requiring *'concentration, patience, strong desire to do so and sufficient time* (20). However early JP education aims focused on providing knowledge about how to maintain functioning of the joints (23) and later on teaching to *protect the joints from invidious and painful stress for thereby to avoid destruction of the joints* (24). Only the current modern concept of JP as a self-management approach (25) acknowledges the need for supporting behavioural changes. Traditional teaching methods such as use of written information, demonstrations, supervised practice and visual aids were successful in providing knowledge and skills (26). However the aims of behavioural change and self-management require other strategies, such as increasing awareness of risk behaviour, aiming to support knowledge, behaviour and health status, strengthening self-efficacy, facilitating intention to take action and social support (16, 25).

Rational for joint protection in current RA management

As effective drug treatment often achieves complete RA remission, it is sometimes assumed that JP is not relevant anymore. However there are several reasons why a number of patients still may develop functional impairments and be in need of occupational therapy and JP education. A considerable proportion of patients does not achieve an acceptable treatment response: ACR20/50/70 criteria show that usually ¼ to ⅓ of RA patients do not respond sufficiently on any available drug (27). Quite a number of patients may also discontinue TNF treatment due to serious side effects (28). There are

also patients with established RA who already developed secondary osteoarthritis and joint deformities prior to the time when more effective drugs (biologicals) became available. And in practice there is usually a delay between onset of symptoms and correct diagnosis inducing appropriate treatment, although this period has decreased to an average of three months in Switzerland (29).

In patients developing functional impairment, hand involvement associated with RA is still one of the major problems. Rating the priorities, hand and finger improvement reached the second highest ranking, behind pain improvement. In 2001, 41.6 % of RA patients rated hand and finger improvements as most relevant, compared to 45% in 1994 (30). Hand JP education is therefore still a key intervention.

Joint protection research

Current evidence

It has been demonstrated that JP education successfully improves function and reduces pain in the short and long-term (25, 31, 32), provided that psycho-educational interventions are applied, as they more successfully facilitate behavioural change and adherence with respect to JP use.

Assessing joint protection interventions

Earlier JP studies assessed the outcome by questionnaire and found self-reported improvement in JP use (33-35). However, self-reporting tends to overestimate behaviour and report attitudes and perceptions, but not the behaviour itself. For this reason, Hammond et al. developed the Joint Protection Behavioural Assessment (JPBA) assessing hand JP use while preparing instant coffee and a snack meal to systematically and objectively evaluate effectiveness of JP interventions (36). This marked a major step in the assessment of JP behaviour.

In **Chapter 3**, the cross-cultural adaption, including the development of an assessment manual, and the assessment of the psychometric properties of a German version of the JPBA in a German-speaking Swiss RA population, is presented.

Determinants of joint protection behavioural change

Facilitators and barriers

Low adherence is considered as one of the main barriers to the effectiveness of a treatment intervention (37). Perception of not being capable of implementing JP behaviour, lack of motivation, not perceiving benefit of adhering, insufficient or inconsistent advice from health professionals and lack of time were identified as reasons for problems with JP adherence (38). This was confirmed by people who did not use JP methods

after education and explained this by: could not recall any of the methods learned or perceived themselves as 'not that bad yet' (25).
Behavioural changes and adhering with treatment are not 'events' but changing states dependent on complex interactions, including attitudes to illness, expectations of health, previous experiences of the illness and social pressures (39). Thus, attitude and cognition play an important role as determinants of behaviour and behaviour change.
In **chapter 4**, a study applying a mixed-methods design with parallel/simultaneous use of qualitative and quantitative approaches is presented. Questionnaires were used to assess the relevance benefits (Pros) of and barriers (Cons) to JP in people with RA and occupational therapists (OTs). Focused interviews with these patients were undertaken to further explore JP concepts and salient beliefs related to JP Pros and Cons.

Self-efficacy

Self-efficacy is considered as one of the most powerful determinants for behavioural changes. Self-efficacy is acquired by direct experience, vicarious experience (role modelling), verbal persuasion and reinterpretation of physiological signals. Direct experience is the most powerful strategy (40). Practice under supervision and at home, goal setting and feedback, observing and exchange with peers in groups, discussions and verbal persuasion are common strategies in JP education. Occupational therapy thus provides learning and practice situations to acquire JP that are also sources for acquiring self-efficacy. As self-efficacy is domain-specific, using a specific JP self-efficacy instrument in JP education may be appropriate. In **chapter 5** the development of a JP self-efficacy scale based on Rasch analysis (41) is presented.

Rational for this randomized controlled trial

In Switzerland an educational approach is usually applied in JP education, providing knowledge and skills by use of conventional teaching methods such as giving information, demonstrations and supervised practice of JP methods. However JP is usually provided in a one-to-one setting and it was therefore unclear, whether the evidence for psycho-educational approaches that was gained in group settings was applicable to an individual intervention.

The experimental intervention of the planned RCT was based on the Pictorial Representation of Illness and Self Measure (PRISM), a measure that provides a visual summary of the perceived burden of illness and its impact on important aspects of a person's life (42, 43). It has demonstrated high therapeutic potential in routine clinical care (44).

When designing the experimental intervention by use of PRISM, the focus was on supporting adherence by targeting (intrinsic) motivation and thus improving the learning process: We hypothesised that meaningful individual goals and resource orientation, i.e. focus on positive life aspects, would have a strong effect on motivation and be efficient means of improving transfer from training to everyday use and of adherence.

The aim of the randomised controlled trial was to evaluate whether individual, resource-oriented JP education in RA patients facilitates JP acquisition and adherence more successfully compared to conventional JP education.

Chapter 6 illustrates the application of PRISM with two cases.

In **Chapters 7 and 8** the short term 3-month results, i.e. two months after the intervention period, and the outcomes after 6 and 12 months respectively, are presented.

Chapter 9 finally summarises and discusses the methodology and the results of the studies and suggests implications of these findings for further clinical care, as well as for future research.

References

1. Lindgren L. The bone and joint decade 2000–2010. Bulletin of the World Health Organization, Vol 89 (9): WHO, 2004.
2. Kremers H, Gabriel S. Epidemiology. In: St. Clair E, Pisetsky D, Haynes B, eds. Rheumatoid arthritis. Philadelphia, PA: Lippincott Williams&Wilkins, 2004:1-10.
3. Allaire S, Wolfe F, Niu J, Lavalley MP, Zhang B, Reisine S. Current risk factors for work disability associated with rheumatoid arthritis: Recent data from a us national cohort. Arthritis Rheum 2009;61:321-8.
4. Scott-DL. Prognosis and clinical course. Rheumatoid arthritis. Philadelphia: Lippincott Williams & Wilkins, 2004:26-41.
5. O'Dell JR. Therapeutic strategies for rheumatoid arthritis. N Engl J Med 2004;350:2591-602.
6. Finckh A, Choi HK, Wolfe F. Progression of radiographic joint damage in different eras: Trends towards milder disease in rheumatoid arthritis are attributable to improved treatment. Ann Rheum Dis 2006;65:1192-7.
7. Finckh A, Simard JF, Duryea J*, et al.* The effectiveness of anti-tumor necrosis factor therapy in preventing progressive radiographic joint damage in rheumatoid arthritis: A population-based study. Arthritis Rheum 2006;54:54-9.
8. Ewert T, Fuessl M, Cieza A*, et al.* Identification of the most common patient problems in patients with chronic conditions using the icf checklist. J Rehabil Med 2004:22-9.
9. Covic T, Tyson G, Spencer D, Howe G. Depression in rheumatoid arthritis patients: Demographic, clinical, and psychological predictors. J Psychosom Res 2006;60:469-76.
10. Dickens C, McGowan L, Clark-Carter D, Creed F. Depression in rheumatoid arthritis: A systematic review of the literature with meta-analysis. Psychosom Med 2002;64:52-60.
11. Backman C, Fairleigh A, Kuchta G. Occupational therapy. In: St. Clair E, Pisetsky D, Haynes B, eds. Rheumatoid arthritis. Philadelphia: Lippincott Williams & Wilkins, 2004:431-9.
12. Stenström C. Physical therapy. In: St. Clair E, Pisetsky D, Haynes B, eds. Rheumatoid arthritis. Philadelphia: Lippincott Williams & Wilkins, 2004:425-30.
13. Eurenius E, Stenstrom CH. Physical activity, physical fitness, and general health perception among individuals with rheumatoid arthritis. Arthritis Rheum 2005;53:48-55.
14. Hammell KW. Dimensions of meaning in the occupations of daily life. Can J Occup Ther 2004;71:296-305.
15. Kirwan JR. Patient education in rheumatoid arthritis. Curr Opin Rheumatol 1990;2:336-9.
16. Taal E, Rasker J, Wiegman O. Patient education and self-management in the rheumatic diseases: A self-efficacy approach. Arthritis Care Res 1996;9:229-38.
17. Burckhardt CS, Lorig K, Moncur C*, et al.* Arthritis and musculoskeletal patient education standards. Arthritis foundation. Arthritis Care Res 1994;7:1-4.
18. Steultjens E, Dekker J, Bouter L, van Schaardenburg D, van Kuyk M, van den Ende C. Occupational therapy for rheumatoid arthritis: A systematic review. Arthritis Rheum 2002;47:672-85.

19. Cordery J, Rocchi M. Joint protection and fatigue management. Rheumatologic rehabilitation: Assessment and management. Bethesda: The American Occupational Therapy Association, Inc, 1998:279-322.
20. Cordery JC. Joint protection; a responsibility of the occupational therapist. Am J Occup Ther 1965;19:285-94.
21. Smith EM, Juvinall RC, Bender LF, Pearson JR. Role of the finger flexors in rheumatoid deformities of the metacarpophalangeal joints. Arthritis Rheum 1964;7:467-80.
22. Melvin J. Rheumatic disease: Occupational therapy and rehabilitation. Philadelphia: FA Davis 1989.
23. Brattström M. Leddskydd och rehabilitering. Lund: Studentlitteratur, 1980.
24. Borgen G, Grønning V, Janborg LH, Kjeken I, Skirbekk K, Utne C. Med leddgikt i hverdagen. Norsk Revmatikerforbund 1992
25. Hammond A, Lincoln N, Sutcliff L. A crossover trial evaluating an educational-behavioural joint protection programme for people with rheumatoid arthritis. Patient Educ Couns 1999;40:1044-51.
26. Hammond A, Lincoln N. The effect of a joint protection education programme for people with rheumatoid arthritis. Clin Rehabil 1999;13:392-400.
27. Smolen JS, Steiner G. Therapeutic strategies for rheumatoid arthritis. Nat Rev Drug Discov 2003;2:473-88.
28. Pan SM, Dehler S, Ciurea A, Ziswiler HR, Gabay C, Finckh A. Comparison of drug retention rates and causes of drug discontinuation between anti-tumor necrosis factor agents in rheumatoid arthritis. Arthritis Rheum 2009;61:560-8.
29. Finckh A, Weber U, Möller B, Scherrer A. Annual report 2008 of the Swiss Clincial Quality Management in Rheumatic Diseases, SCQM. Zurich, 2008.
30. Heiberg T, Finset A, Uhlig T, Kvien TK. Seven year changes in health status and priorities for improvement of health in patients with rheumatoid arthritis. Ann Rheum Dis 2005;64:191-5.
31. Hammond A, Freeman K. The long-term outcomes from a randomized controlled trial of an educational-behavioural joint protection programme for people with rheumatoid arthritis. Clin Rehabil 2004;18:520-8.
32. Hammond A, Freeman K. One-year outcomes of a randomized controlled trial of an educational-behavioural joint protection programme for people with rheumatoid arthritis. Rheumatology (Oxdford) 2001;40:1044-51.
33. Nordenskiold U. Evaluation of assistive devices after a course in joint protection. Int J Technol Assess Health Care 1994;10:293-304.
34. Lindroth Y, Brattstrom M, Bellman I*, et al.* A problem-based education program for patients with rheumatoid arthritis: Evaluation after three and twelve months. Arthritis Care Res 1997;10:325-32.
35. Lindroth Y, Bauman A, Brooks PM, Priestley D. A 5-year follow-up of a controlled trial of an arthritis education programme. Br J Rheumatol 1995;34:647-52.
36. Hammond A, Lincoln N. Development of the joint protection behavior assessment. Arthritis Care Res 1999;12:200-7.
37. Carr A. Barriers to the effectiveness of any intervention in oa. Best Practice and Research in Clinical Rheumatology 2001;15:645-56.
38. Taal E, Rasker JJ, Seydel ER, Wiegman O. Health status, adherence with health recommendations, self-efficacy and social support in patients with rheumatoid arthritis. Patient Educ Couns 1993;20:63-76.
39. Price PE. Education, psychology and 'compliance'. Diabetes Metab Res Rev 2008;24 Suppl 1:S101-5.
40. Bandura A. Self-efficacy: Towards a unifying theory of behaviour change. Psychol Rev 1977;84:191-215.
41. Tennant A, Conaghan PG. The Rasch measurement model in rheumatology: What is it and why use it? When should it be applied, and what should one look for in a rasch paper? Arthritis Rheum 2007;57:1358-62.

42. Buchi S, Sensky T, Sharpe L, Timberlake N. Graphic representation of illness: A novel method of measuring patients' perceptions of the impact of illness. Psychotherapy and psychosomatics 1998;67:222-5.
43. Buchi S, Buddeberg C, Klaghofer R*, et al.* Preliminary validation of prism (pictorial representation of illness and self measure) - a brief method to assess suffering. Psychotherapy & Psychosomatics 2002;71:333-41.
44. Buchi S, Sensky T. Prism: Pictorial representation of illness and self measure. A brief nonverbal measure of illness impact and therapeutic aid in psychosomatic medicine. Psychosomatics 1999;40:314-20.

Chapter 2

Gap between short- and long-term effects of patient education in rheumatoid arthritis patients. A systematic review

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Abstract

Objective: To systematically review educational or psycho-educational interventions for patients with rheumatoid arthritis focusing on long-term effects, especially health status.
Methods: Two independent reviewers appraised the methodologic quality of the included randomized controlled trials, published between 1980 and July 2002.
Results: Validity scores of studies ranged from 3 to 9 (of 11). The 7 educational programs mainly improved knowledge and compliance in the short and long term, but there was no improvement in health status. All 4 psycho-educational programs improved coping behavior in the short term, 2 of them showing a positive long-term effect on physical or psychological health variables.
Conclusion: Methodologically better-designed studies had more difficulties demonstrating positive outcome results. Short-term effects in program targets are generally observed, whereas long-term changes in health status are not convincingly demonstrated. There is a need to find better strategies to enhance the transfer of short-term effects into gains in health status.

Key Words: Patient education; Rheumatoid arthritis; Systematic review; Evaluation

Introduction

Patient education has been defined as "any combination of learning experiences designed to facilitate voluntary adoption of behavior conducive to health" (1). Patient education has an especially important role in completing clinical care: To enable patients to play an active role in the management of their disease and to improve their coping with the disease, including reduced demands for the health care system (2,3).

There is broad agreement on the importance of formal and additionally performed patient education interventions for patients with chronic diseases. Several patient education programs for patients with rheumatic diseases have been developed and evaluated over the last 2 decades (3–9). Moreover, the standards of patient education were revised in 1994 by the National Arthritis Advisory Board for Arthritis Patient Education (9,10).

Giving information is an important target of patient education interventions. The underlying assumption is that more knowledge leads to changes in attitudes and behavior and that health behavior is a result of knowledge, beliefs, and attitudes. The changes attained in health behavior for patients with chronic diseases ought to be substantial enough to change their health status. These assumptions are the theoretic framework on which patient education interventions are built, but they have not been proven to be true (6). Self efficacy (11) is considered an-other important determinant of self-management behavior and there are studies showing associations between self efficacy and health status (12). Changes in self efficacy might not cause changes in health status, but a better health status might influence the performance of self efficacy.

Several reviews on patient education programs for patients with rheumatic diseases have been conducted to determine useful strategies and efficacy (12–18). They evaluated the impact of patient education interventions on knowledge, skills, and health status, such as pain, disability, or psychosocial well being. Because there are purely educational programs (aiming at increasing knowledge and improving performance) and psycho-educational programs (combining teaching intervention activities with behavioral intervention activities to improve coping and change behavior) (15), there is a great variety of program targets and variables measured. Only 1 review was restricted to randomized controlled trials (RCTs) (18).

Some reviews (13–15,17) examined patient education programs for patients with various rheumatic diseases. The results of the reviews distinguishing among the different types of arthritis (15,17) suggest that there may be a difference in efficacy by diagnosis, obtaining more effects for patients with osteoarthritis (OA) than for patients with rheumatoid arthritis (RA), though data are not thoroughly consistent. Age distribution is also divergent in OA and RA patients; RA patients are substantially younger, which may influence the effectiveness of the interventions (15).

All reviews agree that achieved improvements diminish over time, however, only 1 (18) systematically examined the long-term effects, in this case of cognitive-behavioral treatment of RA pain. They found a need for interventions to enhance the long-term

maintenance of treatment gains. This issue is of special interest for patients with such chronic disease as RA.

The current review was performed to systematically collect RCTs examining educational and psycho-educational interventions for RA patients, with focus on their long-term effectiveness. Special attention was paid to assessing the methodologic quality of the studies included. This seemed particularly important to us, because understanding the results of a study means understanding its design, conduct, analysis, and interpretation (19). The authors should give full transparency of their study designs be-cause differences in the quality of methods across studies may indicate that the results of some trials are more biased than others, and the conclusions of an effectiveness study may well depend on the study's methodologic quality.

Methods

Only RCTs involving patients with RA were included in this review. Studies also including patients with other rheumatic diseases (e.g., OA) or more than 1 disease con-currently were excluded. Studies were selected among the scientific publications between 1980 and July 2002, avail-able on Medline, Psychlit, CINAHL, and Cochrane data-base. Additionally, we checked the citation lists to complete our selection.

Inclusion criteria were as follows: 1) RCT studies assessing the effectiveness of a patient education intervention in RA patients; 2) patient education interventions aiming to improve knowledge, health behavior, or skills or to influence the psychological or physical health status; 3) use of pre- and post-interventional measures and 1 long-term assessment, i.e., at least 6 months after treatment; and 4) use of inferential statistics.

Articles were first qualitatively appraised using validity criteria (Table 1) from the Amsterdam-Maastricht Consensus List for Quality Assessment (20) and the criteria set in the Cochrane Reviewers' Handbook (21) for data extraction criteria (Table 2). Two independent reviewers assessed the selected stud ies. Disagreement between the reviewers concerning the validity criteria and data extraction criteria were resolved at a consensus meeting. To decide about the strength of evidence for patient education, the outlines of van Tulder et al (20) were followed: Level A: strong research-based evidence, generally consistent findings in multiple high-quality RCTs; Level B: moderate research-based evidence, generally consistent findings in 1 high-quality RCT or general findings in multiple low-quality RCTs; Level C: limited research-based evidence, 1 RCT (either high or low quality) or inconsistent or contradictory evidence in multiple RCTs; Level D: no research-based evidence, no RCTs.

A high-quality study was defined by a validity score of ~5 (22) and a positive result was defined as a statistically significant result for at least 1 outcome measure.

Table 1. Validity criteria

V1:	Was a method of randomization performed (random [unpredictable] generation of sequence. Stating only "randomization" is scored "unclear")?
V2	Was the treatment allocation concealed (sealed envelopes, randomization by telephone, etc.; allocation cannot be influenced by those responsible for determining eligibility)?
V3	Were the intervention groups similar at baseline regarding prognostic variables (age, sex, duration of disease, severity of symptoms) and baseline scores of outcome measures; or was an adequate statistical adjustment procedure performed?
V4	Was the care provider blinded for the allocation intervention (use of placebo or independent providers for the interventions)? (Patients were not selectively influenced by care providers.)
V5	Were interventions provided to the allocated group only (contamination: e.g., unintended provision of the intervention to members of the control group)?
V6	Were co-interventions avoided or standardized (differential cointerventions lead to bias)?
V7	Was adherence to the intervention acceptable in all groups?
V8	Was the patient blinded to the allocated intervention (use of placebo or naive patients)?
V9	Was the withdrawal/dropout rate described and acceptable (for intervention and follow-up period). Number of dropouts and reasons for withdrawal were specified. The reviewer determines if withdrawal does lead to substantial bias ("no," usually ~5%). V10 Was the outcome assessor blinded to the intervention (placebo, independent assessor of effects)?
V11	Was the timing of outcome assessment comparable in all groups?

Table 2. Data extraction criteria

D1	Were the eligibility criteria specified (diagnosis, duration of symptoms, contraindications, informed consent: "yes" if at least 2 of these criteria are specified)?
D2	Were the therapeutic and control interventions explicitly described (contents, session duration and frequency, number of sessions, length of treatment period)?
D3	Were data concerning relevant outcome measures presented (knowledge, behavior, skills, health status; measures related to intervention goals)?
D4	Were short-term results (immediately after intervention) and a long-term follow-up (at least 6 months after randomization) reported?
D5	Were adverse reactions (unintended negative effects that could be addressed to the intervention) described?
D6	Was the study size for each group described immediately after randomization and at main outcome assessment?
D7	Did the analysis include an intention-to-treat analysis (all randomized patients are reported and analyzed for the most important moments of effect measurements (minus missing values), irrespective of noncompliance or co-interventions)?
D8	Were the point estimates and measures of dispersion presented for the main outcome measures (means and standard deviations, medians and ranges, proportion and %)?

Results

A total of 63 studies evaluating patient education interventions were identified. All 7 reviews (12–18) and another set of 45 studies were excluded because they did not fulfill the key admission criteria: 13 because the diagnosis was not strictly limited to RA, 15 because they were not RCTs, 11 because the follow-up was shorter than 6 months, and 4 studies did not meet several inclusion criteria. One study written in Spanish was dropped, as well as the Dutch version of a study also published in English. Eleven studies (2 3–34) fulfilled all of the given selection criteria and were therefore included in this

review. There was a great variety of interventions, program durations, outcome measures, and follow-up periods.

Quality rating of the studies

The results of the validity criteria rating (Table 1) of the reviewed studies are presented in Table 3. According to these criteria, a total of 7 studies met most of these requirements and were considered high-quality studies (23–29), whereas the 4 other studies were considered poorly designed.

A maximum of 9 of the 11 validity criteria was reached by 2 of the high-quality studies (23,24). In 7 of the 11 studies (26,28–34), the rate of withdrawal or dropout was not given or remained unclear. Five of the 7 educational programs (27,29–32,34) provided no intervention for their controls or put the controls on a waiting list, which was judged as an insufficient blinding procedure. The 3 qualitatively highest-rated studies (23–25) had no negative validity scores.

Some criteria were not possible to judge positively or negatively by the reviewers from the data given in the study. Most problems were due to the method of randomization and the treatment allocation. In 8 studies (26–34), co-interventions were not avoided or necessary medical treatment did not seem to be standardized. Only 4 studies (23,24,26,28) judged the degree of adherence to the intervention.

Studies with higher positive validity scores clearly had higher scores on the data extraction criteria list. Seven studies with validity scores of at least 5 (23–29) had a mean value of positive data extraction criteria of 5.6; whereas 4 studies (30–34) with validity scores ~5 had a mean value of positive data extraction criteria of 2.8.

Table 3. Quality assessment of studies on patient education with RA patients (in order of quality ranking)*

Study (reference no.)	Type of Intervention	Validity score Positive score (total 11)	Validity criteria negative score	Validity criteria unclear score	Data extraction (total 8 criteria)
Kraaimaat (23)	Psycho-educational	V3, V4, V5, V6, V7, V8, V9, V10, V11	—	V1, V2	D1, D2, D3, D4, D6, D8
Parker (24)	Psycho-educational	V3, V4, V5, V6, V7, V8, V9, V10, V11	—	V1, V2	D1, D2, D3, D4, D6,
Brus (25)	Educational	V3, V4, V6, V8, V9, V10, V11	—	V1, V2, V5, V7	D1, D2, D3, D4, D6, D8
Hammond (26)	Educational	V3, V4, V5, V8, V10, V11	V9	V1, V2, V6, V7	D1, D2, D3, D4, D6, D7, D8
Helliwell (27)	Educational	V1, V2, V3, V9, V10, V11	V8	V4, V5, V6, V7	D1, D2, D3, D4, D7, D8
Parker (28)	Psycho-educational	V1, V3, V4, V5, V8, V11	V9	V2, V6, V7, V10	D1, D2, D3, D4,
Taal (29)	Educational	V3, V5, V7, V8, V11	V9	V1, V2, V4, V6, V10	D1, D2, D3, D4, D6
Lindroth (30)	Educational	V4, V5, V10, V11	V8, V9	V1, V2, V3, V6, V7	D2, D3, D4,
Barlow (31/32)	Educational	V3, V4, V10, V11	V5, V8, V9	V1, V2, V6, V7	D3, D4, D8
Bradley (33)	Psycho-educational	V5, V8, V10	V9	V1, V2, V3, V4, V6, V7, V11	D1, D3, D4, D6, D8
Scholten (34)	Educational	V4, V10, V11	V6, V8, V9	V1, V2, V3, V5, V7	D2, D4, D8

For definitions of V1–V11 and D1–D8, see Tables 1 and 2. RA ~ rheumatoid arthritis.

Description of the studies

Seven programs provided classic education to teach knowledge and specifically needed skills (Table 4), whereas 4 studies offered cognitive-behavioral therapy with focus on coping strategies and psychological support (Table 5). Only 1 study, testing the effects of mailed educational leaflets (31,32), was not organized as group therapy.

Program duration ranged between 4 and 15 weeks (median 7 interventions). Eight programs were organized as weekly 1.5–2-hour sessions; 2 of them with reinforcement meetings after program conclusion (25,26). Three pro-grams were organized differently: a 1-week hospital stay with a 12-month support program (28), 9 afternoon sessions within 2 weeks (34), and a low-level intervention of an educational leaflet mailing (31,32).

Six of the 7 educational programs provided no intervention for the control groups in addition to ongoing clinical care (25–27,30–32,34); an alternative therapy (physiotherapy) was offered in 1 study (29). In contrast to this, all 4 psycho-educational studies had 2 control groups: 1 group receiving the standard therapy and 1 receiving no intervention (23,24,28,33).

A minimum follow-up period of 6 months for evaluating a long-term effect was given as selection criteria. There were follow-ups of up to 15 months, with 2 studies presenting 2 follow-up measurements (23,24).

Table 4. Description of educational programs*

Study (reference no.)	Intervention	Authors' aim of study	Duration of intervention	Control group	Disease duration	Study size†	Long-term followup
Brus et al (25)	Educational group therapy	Evaluate effects of an educational program on compliance with sulfasalazine therapy/prescription with physical exercise and endurance exercise/prescriptions for ergonomic and on health	4 weeks (4 weekly 2-hour sessions); reinforcement meetings after 4 and 8 months	No intervention‡	<3 years	n = 65 EG 32 (3/4/0) CG 33 (2/1/0)	6 and 12 months
Hammond et al (26)	Educational group therapy	Evaluate an educational-behavioral joint protection program for improving adherence with joint protection Identify factors influencing adherence	4 weeks (4 weekly 2-hour sessions); optional home visit within 2 weeks after program	Waiting list (crossover trial)	9.8 years (SD 8.0)	n = 35 EG1 17(0/4/0) CG1 18(0/4/0)	4 and 6 months
Helliwell et al (27)	Educational group therapy	Record effects of an education program on radiologic damage and quality of life in early RA	4 weeks (4 weekly 2-hour sessions)	No intervention†	3.5 years (range 0–5)	n = 77 EG 43 (0/2/0) CG 34 (0/0/0)	12 months
Taal et al (29)	Educational group therapy plus physiotherapy	Evaluate effects of participation in group education program on health status, behavior, self efficacy, outcome expectation, knowledge	5 weeks (5 weekly 2-hour sessions)	Physiotherapy	3.9 years (range 1–20)	n = 75 EG 38(7/0/4) PT 37(7/0/0)	14 months
Lindroth et al (30)	Educational group therapy	Evaluate effect of program on increase of individual's behavior in practicing exercise and work simplification and if this leads to a better outcome (pain and disability)	8 weeks (8 weekly 2.5-hour sessions)	No intervention†	11 years (SD 8)	n = 100 (4/0/0) EG 49 (1/4/0) CG 47 (3/1/0)	12 months
Barlow et al 1998 (31,32)	Mailing of educational RA-related leaflets to individuals with RA	Evaluate if increased knowledge is maintained at 6 months followup and relationships between knowledge and anxiety and knowledge and disease duration	3 weeks (second assessment)	Waiting list (related mailing)	16.0 years (SD 11.7)	n = 142 (0/34/0) EG 53 (0/11/0) CG 55 (0/13/0)	6 months
Scholten et al 1999 (34)	Educational group therapy	Assess the sustainable benefits of a professional, multidisciplinary training program for patients with RA	9 days (9 half days within 2 weeks)	No intervention†	8.9 years (SD 1.2)	n = 68 EG 38 (0/0/0) CG 30 (0/0/0) n = 64 after 60 months	12 months 60 months

* EG = educated group; CG = control group with no intervention; RA = rheumatoid arthritis.
† n = number of randomized patients (dropouts/lost to followup/exclusions for nonadherence to intervention).
‡ No intervention mean ongoing rheumatologic care, but no adjunct therapy.

Table 5. Description of psychoeducational programs*

Study (reference no.)	Interventions	Author's aim of study	Duration of intervention	Control groups†	Disease duration	Study size‡	Long-term followup
Kraaimaat et al (23)	CBT group	Evaluate effect of CBT in comparison to standard OT and no treatment	10 weeks	Standard group OT or no intervention	15.6 years (SD 12.7)	n = 77 CBT 27 (0/0/3) OT 31 (0/0/3) CG 19 (0/0/0)	6 months
Parker et al (24)	Stress management group therapy plus ongoing rheumatologic care	Examine the effectiveness of a stress-management program for improving clinical outcomes in patients with RA	10 weeks (10 weekly 1.5-hour sessions) plus 15-month maintenance program (at least 5 visits)	Attention control group or no intervention	12.2 years (SD 9.8)	n = 141 SM 47 (1/0/2) AC 49 (0/0/4) CG 45 (1/0/0)	15 months
Parker et al (28)	CBT pain management group	Examine the effectiveness of a CBT pain management program	1 week hospital stay 12 months support group program	General educational program group or no intervention	11.4 years	n = 83 CBT 29 (0/0/0) GP 26 (0/0/0) CG 28 (0/0/0)	12 months
Bradley et al (33)	CBT group	Evaluation of CBT in comparison to STG and no intervention on pain reduction and coping strategies	CBT: 15 sessions 5 individual thermal biofeedback training and 10 group sessions	STG or no intervention	11.5 years (SD 11.41)	n = 68 (2/0/0) CBT 17 (6/1/0) STG 18 (4/1/0) CG 18 (1/0/0)	6 months

* CBT = cognitive-behavioral therapy; OT = occupational therapy; CG = control group with no intervention; SM = stress management; AC = attention control; RA = rheumatoid arthritis; GP = general educational program; STG = structured social group therapy.
† No intervention means ongoing rheumatologic care, but no adjunct therapy.
‡ n = number of randomized patients (drop outs/lost to followup/exclusions for nonadherence to intervention).

Patient education interventions.

All studies assessed several dimensions targeted by patient education. Knowledge improvement was essential in educational programs, whereas it was usually not a goal in psycho-educational programs. All educational programs assessed compliance and performance, whereas the psycho-educational studies focused on (pain-) coping behavior. Physical and psycho-logical health status variables were measured in all studies. The 7 educational programs improved mainly knowledge and compliance in the short and long term, but no improvement in health status could be found. All 4 psycho-educational programs generally improved coping behavior in the short term, 2 of them showing a positive effect on physical or psychological health variables in the long term.

All studies measured and reported changes over time for each group, but only few studies made comparisons between groups (27,28,32). The detailed results of the evaluation are presented in Tables 6 and 7. To decide about the strength of evidence for the various interventions, the out-lines of van Tulder (20) were followed.

There were 7 studies aiming to increase knowledge (23,26,27,29–32,34). They all obtained this effect, which mostly persisted for the long term. In 1 study (27), the control group also increased their knowledge. There is strong evidence that patient education increases knowledge in the short and long term, because there were consistent findings in all high-quality studies aiming to improve knowledge (23,26,27,29).

Coping improves the ability to manage the disease. Special emphasis for patients with RA is on coping with pain. Six studies (23,24,28,30,33,34) examined coping abilities before and after educational interventions. There is strong evidence for an increase in coping after patient education, because all 3 high-quality studies (23,24,28) showed at least 1 pain-coping behavior that improved significantly after intervention. However, there is only limited evidence for long-term increase of coping behavior; the results in the long term were inconsistent in high-quality studies (23,24,28) and low-quality studies (30,33,34).

Compliance is an important goal in all educational pro-grams. It is the fulfilling of the medical or therapeutic suggestions helpful for patients with RA, such as medication intake, physical exercise, energy conservation, and joint protection. Six educational interventions (25–27, 29,30,34) targeted compliance in various dimensions. There was strong evidence for an increase of long-term compliance in general; only 1 (high quality) study (27) did not find any significant change in compliance. However, evidence for specific compliance regarding joint protection and medication intake in the long term was moderate; results of high-quality studies (25,26) were inconsistent, whereas low-quality studies had positive long-term results (30,34). Compliance as measured with a general compliance questionnaire remained unchanged (27).

The concept of self efficacy is thought to be of major importance for patients with RA (12,35), enabling them to follow the requirements and to successfully manage their disease. But only 3 programs, 2 educational and 1 psycho-educational (24,26,29), targeted self efficacy. All these studies were of high methodologic quality but had incon-

sistent results. The evidence for the effect of patient education on self efficacy is therefore moderate.

The most important psychological health status variables measured were depression, anxiety, helplessness, self confidence, social support, and relationship with friends. Only 1 study did not measure psychological health status (29). All but 1 (24) high-quality study were not able to show any change in psychological health status, neither in the short term nor in the long term. One study (23) revealed a disease-related increase in depression but also a decrease in social support at the 6-month follow-up. There is limited evidence of patient education influencing psychological health status.

Among the health status variables are physical functioning, pain, disability, and hand function. Pain is the major problem for patients with RA, but there seems to be little impact on pain relief by patient education. All studies (23–34) measured physical health status. One study (23) even showed a progressive worsening of pain for all participating patients at the follow-up measurement. Only 1 high-quality study (24) showed a positive change in pain in the short and long term. No long-term changes were shown in disability and physical function in any study. Therefore, there is limited evidence for patient education influencing physical health status.

Table 6. Evaluation of educational programs (results)

Study (quality ranking)	Knowledge T1/T2	Coping T1/T2	Compliance or performance T1/T2	Self efficacy T1/T2	Psychological health status T1/T2	Physical health status T1/T2
Brus et al (3) T1 = 4 weeks T2 = 12 months	NA	NA	Medication All NS Rest EG +/+ CG 0/0 Joint protection EG +/0 CG 0/0	NA	Psychological functioning NS	Physical functioning All NS RA activity All NS
Hammond et al (4) T1 = 4 weeks T2 = 6 months	Joint protection EG +/ND CG 0/ND	NA	Joint protection EG ND/+ CG ND/+	NS	Helplessness NS	Pain, strength, hand function; physical functioning All NS
Helliwell et al (5) T1 = 4 weeks T2 = 12 months	RA EG +/+ CG +/+ EG:CG +/+	NA	NS	NA	QOL NS	Radiographic scores All NS
Taal et al (7) T1 = 5 weeks T2 = 14 months	RA EG +/+ CG 0/0	NA	Physical activity EG +/+ CG 0/0	EG +/+ CG 0/0	NA	Physical functioning, pain EG +/0 CG 0/0
Lindroth et al (8) T1 = 8 weeks T2 = 12 months	RA EG ND/+ CG ND/0	Pain relief capacity EG ND/+ CG ND/+	Joint protection EG ND/+ CG ND/0	NA	Depression, social relations, fears All NS Self confidence EG +/+ CG 0/0	Pain EG +/0 CG 0/0
Barlow et al (9) T1 = 3 weeks T2 = 6 months	RA EG +/+ CG 0/0	NA	NA	NA	Depression EG +/+ CG 0/0 EG:CG +/+	Pain EG +/+ CG 0/+
Scholten et al (11) T1 = 9 days T2 = 12 months	RA EG +/+ CG 0/0	Coping with disease EG +/+ CG 0/0 Distraction EG +/+ CG 0/0	Joint protection, physical activity, rest, medication EG +/+ CG 0/0	NA	Depression EG +/+ CG 0/0	Disability EG +/+ CG 0/0

Table 7. Evaluation of psychoeducational programs*

Study (quality ranking)	Knowledge T1/T2	Pain coping behavior T1/T2	Compliance T1/T2	Self efficacy T1/T2	Psychological health status T1/T2	Physical health status T1/T2
Kraaimaat et al (1) T1 = 10 weeks T2 = 6 months	CBT +/0 OT +/0 CG 0/0	Distraction CBT +/0 OT 0/0 CG 0/0	NA	NA	Depression CBT 0/− OT 0/− CG 0/− Social support CBT 0/− OT 0/− CG 0/−	Pain CBT 0/− OT 0/− CG 0/−
Parker et al (2) T1 = 10 weeks plus 15 months T2 = 15 months	NA	Coping strategies SM +/+ AC 0/0 CG 0/0	NA	SM +/+ AC 0/0 CG 0/0	Helplessness SM +/+ AC 0/0 CG 0/0	Pain SM +/+ AC 0/0 CG 0/0
Parker et al (6) T1 = 1 week inpatient plus 12 months T2 = 12 months	NA	Diverting attention CBT:AC/CG ND/+ Control over pain CBT:AC/CG ND/+ Decreasing or ignoring pain CBT:CG ND/+ Catastrophizing CBT:CG/AC:CG ND/+	NA	NA	All NS	All NS
Bradley et al (10) T1 = 15 weeks T2 = 6 months	NA	Pain behavior CBT +/0 SGT +/0	NA	NA	Anxiety CBT +/+ SGT +/0	Pain intensity CBT +/+ SGT +/0

* T1 = time 1, immediately after intervention; T2 = time 2, after followup; CBT = cognitive-behavior therapy group; NA = not applicable; OT = occupational therapy group, CG = control group; + = significant positive change; 0 = no change; − = significant negative change; SM = stress management group; AC = attention control group; GP = general education program group; ND = not done; SGT = structured social group therapy.

Discussion

The goal of this review was to perform a systematic review with methodologic appraisal and to evaluate the effectiveness of patient education interventions for patients with RA, emphasizing the long-term effects. Nearly all studies included multiple health status measurements, but often no primary outcomes were defined. Goals and interventions varied greatly and programs were organized differently, which made it difficult to decide about the most successful education interventions.

Positive short-term effects of patient education targets for RA patients are generally observed, e.g., knowledge in the educational programs or coping behavior in the psycho-educational programs. There is only limited evidence for long-term changes in health status. This is consistent with other studies (12,18) in which effects of patient education for patients with rheumatic diseases were apparent immediately after the end of program, possibly lasting for some weeks, but vanishing over time. Moreover, because patient education interventions usually are provided in addition to standard medical care, only supplementary effects might be expected (12).

Methodologically better-designed studies had more difficulties in demonstrating positive outcome results. Methodologic problems, such as unclear intervention procedures, possible co-interventions, few specified eligibility criteria, no given dropout rate, and no intention-to-treat analysis, may result in potential bias by overestimating or underestimating the demonstrated effects. Indeed, this may mislead the authors in the interpretation of their results; on the other hand, methodologic issues that are not described or not conducted may prevent readers from obtaining full transparency and understanding of the study presented.

We will now discuss possible reasons for the unsatisfying long-term results and issues for directly enhancing compliance and long-term adherence to maintain the short-term program targets.

The characteristics of RA, disease duration, and the progressive nature of RA may play a role in long-term results. There is evidence that studies using only RA patients show a smaller effect than studies with other rheumatic diseases or mixed study populations (17). Patients with recent-onset disease have been shown to benefit the most from patient education; for example, cognitive-behavioral therapy was an effective intervention to change pain coping behavior (23). However, others (31,32) demonstrated in their study that the patients' level of knowledge and the increase of knowledge did not differ, regard-less of disease duration. The progressive character of RA may weaken changes and diminish them over time. The methodologically best-rated study (23) found very moderate changes and no long-term effects; instead, a progressive deterioration due to the disease for all study groups could be demonstrated.

There is an implicit assumption that changes in behavior lead to changes in health, but in practice there is no consistent confirmation of this relationship or even causality (6,35). Another important reason for the difficulty of obtaining long-term effects may be the fact that we still do not understand which patient education interventions are really effective and which mechanisms make them work. Moreover, the interventions

are based on different theoretical frameworks and assumptions and it is not really clear which patients will do best with which interventions and when.

Although some state that knowledge is the cornerstone on which all education is built (30), others consider interventions that directly focus on changing behavior (e.g., self efficacy) as more effective (36). There is a clear trend away from aiming at knowledge as a basic outcome (14), and the variety of target variables—and therefore outcomes—has impressively increased in the last years. Actually, there is emphasis on compliance, pain-coping behavior, and psychological variables (25).

Generally, there have been few attempts to target compliance directly and there are only limited strategies about how to enhance long-term adherence to the program. Compliance was not an issue in most of the reviewed studies. Only 4 studies (23,24,26,28) measured the adherence rate to the program or the additional exercise time at home. Neither the few dropouts due to nonadherence to study sessions (23) nor additional exercising at home (24) influenced the study results. One study (25) found high levels of compliance in patients with recent-onset RA combined with low disease activity, which, however, is opposed to the findings of another study (37).

Long-term compliance and adherence to programs may be important issues for any therapeutic intervention and may play a key role for the effectiveness of an intervention. Health care professionals are becoming aware of this situation and strategies to support compliance, at least in the short term, are being adopted. Interventions are being tailored individually, based on the goal agreement between patients and health care professionals; the most important concepts for supporting behavioral changes, such as enhancing self efficacy, supporting the intention to change, and making plans about how to target the goals, are being adopted (38); and reinforcement meetings are being offered. However, self-reported adherence in the long term to medication consumption, home exercise, and splint use is not satisfying (25,39).

The greater the degree of behavioral change (e.g., in exercise, relaxation, sleep, diet, medication, joint protection, strategies for managing anxiety and depression, communication skills, etc.) required from a patient in 1 interventional setting, the less the adherence (26).

Scores of self efficacy (40,41) and—an opposed but similar concept—perceived helplessness (42) seem to be important predictors of adherence. Taal et al found that people with more self efficacy are more likely to cooperate, also in the long term (12). However, an RCT by the same authors (29) revealed that group education was beneficial only for the behavior for which the patients already had high self-efficacy scores prior to interventions and that high self-efficacy scores at baseline made it difficult to improve further. Adherence to health recommendations was not correlated with functional disability, pain, or other aspects of health status; however, adherence problems were negatively correlated with low self-efficacy expectations of the patients about coping with the disease. Another study (28) stated that control over pain and the ability to decrease pain are typical areas of self efficacy, where an immediate benefit may improve self efficacy and, therefore, support adherence. People with high scores on the Arthritis Helplessness Index (43) are less likely to adopt problem-solving behavior (26);

likewise, increased adherence is associated with an increase of perceived control of arthritis (i.e., lower helplessness) (26,28), an in-crease of ability to cope with pain, and a decrease in pain intensity. Indeed, less helplessness may well enable people to learn better: People in the low-anxiety group scored significantly better in knowledge at baseline and knowledge increase during the study, compared with the high-anxiety group (25).

In conclusion, successful long-term adaptation is associated with active coping, in which psychological health status shows the patient's readiness to play an active role (23). Methodologic problems may result in potential bias by overestimating or underestimating the demonstrated effects. In effectiveness studies, attention should not only be paid to the evaluation of the given intervention, but equally to the methodologic issues and its reporting.

The critical appraisal of RCTs about the effectiveness of patient education in RA revealed that effects are not obvious, especially long-term effects. There may be a need to reevaluate the theoretical framework of behavioral change and strategies to enhance the patient's long-term adherence to educational or psycho-educational programs. These programs should be tested in longitudinal studies, because only adherent patients may transfer their short-term gains in knowledge and behavioral skills into gains in health status and bring about an effective intervention.

References

1. Green LW. Determining the impact and effectiveness of health education as it relates to federal policy. Health Educ Mongr 1978;6 Suppl 28:66.
2. Young LD, Bradley LA, Turner RA. Decreases in health care resource utilization in patients with rheumatoid arthritis following a cognitive behavioral intervention. Biofeedback Self Regul 1995;20:259–68.
3. Lorig K, Mazonson PD, Holman HR. Evidence suggesting that health education for self-management in patients with chronic arthritis has sustained health benefits while reducing health care costs. Arthritis Rheum 1993;36:439–46.
4. Lorig K. Arthritis self-management: a patient education pro-gram. Rehabil Nurs 1982;7:16–20.
5. Lorig K. Arthritis self-management: a five-year history of a patient education program. Nurs Clin North Am 1984;19:637– 45.
6. Lorig K, Laurin J. Some notions about assumptions underlying health education. Health Educ Q 1985;12:231–43.
7. Lorig K, Lubeck D, Kraines RG, Seleznick M, Holman HR. Outcomes of self-help education for patients with arthritis. Arthritis Rheum 1985;28:680–5.
8. Lorig K, Gonzalez V. The integration of theory with practice: a 12-year case study. Health Educ Q 1992;19:355–68.
9. Lorig K, Visser A. Arthritis patient education standards: a model for the future. Patient Educ Couns 1994;24:3–7.
10. Burckhardt CS, Lorig K, Moncur C, Melvin J, Beardmore T, Boyd M, et al. Arthritis and musculoskeletal patient education standards: Arthritis Foundation. Arthritis Care Res 1994; 7:1–4.
11. Bandura A. Social foundations of thought and action: a social cognitive theory. Englewood Cliffs (NJ): Prentice Hall; 1986.
12. Taal E, Rasker JJ, Wiegman O. Patient education and self-management in the rheumatic diseases: a self-efficacy approach. Arthritis Care Res 1996,9:229–38.

13. Lorig K, Konkol L, Gonzalez V. Arthritis patient education: a review of the literature. Patient Educ Couns 1987;10:207–52.
14. Hirano PC, Laurent DD, Lorig K. Arthritis patient education studies, 1987–1991: a review of the literature. Patient Educ Couns 1994;24:9–54.
15. Hawley DJ. Psycho-educational interventions in the treatment of arthritis. Bailliere's Clin Rheumatol 1995;9:803–23.
16. Taal E, Rasker JJ, Wiegman O. Group education for rheumatoid arthritis patients. Semin Arthritis Rheum 1997;26:805– 16.
17. Superio-Cabuslay E, Ward MM, Lorig K. Patient education interventions in osteoarthritis and rheumatoid arthritis: a meta-analytic comparison with nonsteroidal anti-inflammatory drug treatment. Arthritis Care Res 1996;9:292–301.
18. Keefe JF, Van Horn Y. Cognitive-behavioral treatment of rheumatoid arthritis pain. Arthritis Care Res 1993;4:213–22.
19. Moher D, Jadad AR, Tugwell P. Assessing the quality of randomized controlled trials. Int J Technol Assess Health Care 1996;12:195–208.
20. Van Tulder MW, Assendelft WJ, Koes BW, Bouter LM. Methodologic guidelines for systematic reviews in the Cochrane Collaboration Back Review Group for Spinal Disorders. Spine 1997;22:2323–30.
21. Clarke M, Oxman AD, editors. Cochrane reviewers' handbook 4.0. Oxford (UK): The Cochrane Collaboration; 1999.
22. Van der Windth DAWA, van der Heiden GJMG, van den Berg SGM, ter Riet G, de Winter AF, Bouter LM. Ultrasound therapy for musculosceletal disorders: a systematic review. Pain 1999;81:257–71.
23. Kraaimaat FW, Brons MR, Geenen R, Bijlsma JW. The effect of cognitive behavior therapy in patients with rheumatoid arthritis. Behav Res Ther 1995;33:487–95.
24. Parker JC, Smarr KL, Buckelew SP, Stucky-Ropp RC, Hewett JE, Johnson JC, et al. Effects of stress management on clinical outcomes in rheumatoid arthritis. Arthritis Rheum 1995;38: 1807–18.
25. Brus HL, van de Laar MA, Taal E, Rasker JJ, Wiegman O. Effects of patient education on compliance with basic treatment regimens and health in recent onset active rheumatoid arthritis. Ann Rheum Dis 1998;57:146–51.
26. Hammond A, Lincoln N, Sutcliffe L. A crossover trial evaluating an educational-behavioural joint protection programme for people with rheumatoid arthritis. Patient Educ Couns 1999;37:19–32.
27. Helliwell PS, O'Hara M, Holdsworth J, Hesselden A, King T, Evans P. A 12-month randomized controlled trial of patient education on radiographic changes and quality of life in early rheumatoid arthritis. Rheumatology (Oxford) 1999;38:303–8.
28. Parker JC, Frank RG, Beck NC, Smarr KL, Buescher KL, Phil-lips LR, et al. Pain management in rheumatoid arthritis patients: a cognitive-behavioral approach. Arthritis Rheum 1988;31:593–601.
29. Taal E, Rasker JJ, Seydel ER, Wiegman O. Group education for patients with rheumatoid arthritis. Patient Educ Couns 1993; 20:63–76.
30. Lindroth Y, Brattstroem M, Bellman I, Ekestaf G, Olofsson Y, Stroembeck B, et al. A problem-based education program for patients with rheumatoid arthritis: evaluation after three and twelve months. Arthritis Care Res 1997;10:325–32.
31. Barlow JH, Pennington DC, Bishop PE. Patient education leaf-lets for people with rheumatoid arthritis: a controlled study. Psychol Health Med 1997;2;221–35.
32. Barlow JH, Wright CC. Knowledge in patients with rheumatoid arthritis: a longer term follow-up of a randomized con-trolled study of patient education leaflets. Br J Rheumatol 1998;37:373–6.
33. Bradley LA, Young LD, Anderson KO, Turner RA, Agudelo CA, McDaniel LK, et al. Effects of psychological therapy on pain behavior of rheumatoid arthritis patients: treatment out-come and six-month follow-up. Arthritis Rheum 1987;30: 110 5–14.
34. Scholten C, Brodowicz T, Graninger W, Gardavsky I, Pils K, Pesau B, et al. Persistent functional and social benefit 5 years after a multidisciplinary arthritis training program. Arch Phys Med Rehabil 1999;80:1282–7.

35. Daltroy LH, Liang MM. Arthritis education: opportunities and state of the art. Health Educ Q 1993;20:3–16.
36. Lorig K, Seleznick M, Lubeck D, Ung E, Chastain RL, Holman HR. The beneficial outcomes of the arthritis self-management course are not adequately explained by behavior change. Arthritis Rheum 1989;32:91–5.
37. Owen SG, Friesen WT, Roberts MS, Flux W. Determinants of compliance in rheumatoid arthritic patients assessed in their home environment. Br J Rheumatol 1985;24:313–20.
38. Ehlebracht-Ko¨nig I, Bo¨nisch A. [Principals of rheumatologic patient education: theoretical principals and didactical is-sues] Z Rheumatol 2002;61:39–47.
39. Bradley LA. Adherence with treatment regimens among adult rheumatoid arthritis patients: current status and future directions. Arthritis Care Res 1989;2:S33–9.
40. Scherer YK, Bruce S. Knowledge, attitudes, and self-efficacy and compliance with medical regimen, number of emergency department visits, and hospitalizations in adults with asthma. Heart Lung 2001;30:250–7.
41. Sullum J, Clark MM, King TK. Predictors of exercise relapse in a college population. J Am Coll Health 2000;48:175–80.
42. Stein MJ, Wallston KA, Nicassio PM, Castner NM. Correlates of a clinical classification schema for the arthritis helplessness subscale. Arthritis Rheum 1988;31:876–81.
43. Nicassio PM, Wallston KA, Callahan LF, Herbert M, Pincus T. The measurement of helplessness in rheumatoid arthritis: the development of the Arthritis Helplessness Index. J Rheumatol 1985;12:462–7.

Chapter 3

Development and validation of a German version of the Joint Protection Behavior Assessment in patients with rheumatoid arthritis

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Abstract

Objective: Joint protection (JP) is an important part of the treatment concept for patients with rheumatoid arthritis (RA). The Joint Protection Behavior Assessment short form (JPBA-S) assesses the use of hand JP methods by patients with RA while preparing a hot drink. The purpose of this study was to develop a German version of the JPBA-S (D-JPBA-S) and to test its validity and reliability.

Methods: A manual was developed through consensus with 8 occupational therapist (OT) experts as the reference for assessing patients' JP behavior. Twenty-four patients with RA and 10 healthy individuals were videotaped while performing 10 tasks reflecting the activity of preparing instant coffee. Recordings were repeated after 3 months for test–retest analysis. One rater assessed all available patient recordings (n ~ 23, recorded twice) for test–retest reliability. The video recordings of 10 randomly selected patients and all healthy individuals were independently assessed for interrater reliability by 6 OTs who were explicitly asked to follow the manual. Rasch analysis was performed to test construct validity and transform ordinal raw data into interval data for reliability calculations.

Results: Nine of the 10 tasks fit the Rasch model. The D-JPBA-S, consisting of 9 valid tasks, had an intraclass correlation coefficient of 0.77 for interrater reliability and 0.71 for test–retest reliability.

Conclusion: The D-JPBA-S provides a valid and reliable instrument for assessing JP behavior of patients with RA and can be used in German-speaking countries.

Keywords: Validation; Joint protection behavior; Rheumatoid arthritis; Rasch analysis; Occupational therapy.

Introduction

Individuals with rheumatoid arthritis (RA) experience physical impairment and functional limitations, even though impressive advances in drug treatment have been achieved (1). A multidisciplinary approach in the management of RA is important, with physiotherapy and occupational therapy aiming at maintaining or improving independence and quality of life (2,3).

Hand involvement during the course of the disease occurs inevitably. Within 5 years of onset, finger and wrist joints are affected (4) and destruction of the dominant hand is more frequently observed (5). Joint protection (JP) is therefore an important intervention. Principles of JP have been developed based on anatomic and biomechanical research to guide occupational therapists (OTs) in their work with patients with RA (6), e.g., altering working methods (use of proximal joints, dynamic activities), energy conservation (balance between activity and rest), and using assistive devices.

JP has beneficial short-term effects on pain and function in patients with established RA and moderate functional problems (7,8). Using assistive devices reduces pain during task performance (7) and altering working methods reduces difficulties in activities of daily living (8). If JP is taught using behavioral education methods, it can also have a long-term impact on reducing pain and maintaining function for individuals with less than 5 years' disease duration (9–11). JP is also taught as a preventive intervention to patients with recent disease onset. However, its effectiveness at this early stage has not yet been convincingly demonstrated (12).

Discrepancy has been found between self-reported and observed JP behavior (8). An assessment instrument that systematically and objectively evaluates effectiveness of JP interventions is needed. Hammond and Lincoln developed and evaluated the Joint Protection Behavior Assessment (JPBA) (13) assessing JP behavior while preparing instant coffee and a snack, because most JP methods that are taught clinically focus on protecting hand and wrist joints during kitchen activities. In the JPBA, 5 JP principles (6) are assessed while performing finger-wrist activities: reducing effort using labor-saving gadgets and assistive devices, avoiding lifting, and having good workplace organization; distributing load over several joints; using joints in stable positions; using stronger, larger (proximal) joints; and avoiding positions of deformity.

The original JPBA consists of 20 tasks integrating these JP principles. Several aspects of validity and reliability of the JPBA have been extensively examined (13,14) and the JPBA has been used in clinical studies (9–11,15,16). A short version of the JPBA (JPBA-S), consisting of 10 tasks for the activity of preparing instant coffee, has been found to be reliable compared with the full-length JPBA (Spearman's correlation 0.94) (14). The cultural adaptation and validation of a German version was therefore based on the short form. Preparing instant coffee is also a common activity in Switzerland and requires little time, which minimizes the risk of individuals with RA becoming fatigued.

The purpose of the present study was to cross-culturally adapt the original JPBA-S to a German (Deutsch) version (D-JPBA-S) and to develop an assessment manual and assess the psychometric properties in a German-speaking Swiss population with RA.

Before assessing interrater, intrarater, and test–retest reliability, special attention was paid to the construct validity of the D-JPBA-S.

Participants and Methods

Participants

Eight OTs from different hospital rheumatology departments in Zurich, Switzerland who were experienced in treating patients with RA and teaching JP were invited to participate in the development of the German manual. We videotaped the JP performance of 24 patients who were consecutively recruited from the out-patient facility of the Department of Rheumatology, University Hospital Zurich between June and July 2004. All patients fulfilled the 1987 American College of Rheumatology (formerly the American Rheumatism Association) classification criteria for RA (17); were receiving stable disease-modifying antirheumatic drug (DMARD) treatment, including anti–tumor necrosis factor treatment, steroids, and nonsteroidal antiinflammatory drugs, for at least 4 weeks; and had mild to moderate disease activity (Disease Activity Score in 28 joints [DAS28] ~5.1).

All participants had attended at least 1 JP instruction session since onset of the disease. Patients with severe RA and functional limitations preventing JP behavior or independent task performance were excluded. All but 1 patient (due to exacerbation of comorbidities) participated in the test– retest recordings after 2–3 months (n ~ 23). All patients had stable disease activity during this period. Self-perceived disease activity, measured with the Rheumatoid Arthritis Disease Activity Index (RADAI), and erythrocyte sedimentation rate remained unchanged (Table 1). However, the DMARD dose was slightly increased in 2 patients. Ten non–health professional employees of the University Hospital without health problems, matched in age and sex to the RA group, participated as controls (Table 1).

The local research ethics committee approved the study protocol and all individuals provided informed consent prior to participation. Six therapists (4 OTs and 2 physiotherapists [PTs]), recruited from different rheumatology departments in Zurich, assessed the video recordings.

Table 1. Demographic and clinical characteristics of study participants*

Characteristic	Healthy controls (n ~ 10)	RA patients (n ~ 23) Baseline	3 months	Correlation with D-JPBA-S (R) at baseline
Women/men, no.	7/3	18/5		
Age, median (IQR) years	57 (47–63)	63 (47–70)		
Disease duration, median (IQR) years	NA	11 (7–18)		
Hochberg functional class, median (IQR)	NA	2 (1–4)	NM	0.44†
DMARDs, no. of patients	NA	22	22	
Steroids, no. of patients	NA	11	11	
NSAIDs, no. of patients	NA	10	10	
DAS28	NA	3.2 ~ 1.5	NM	0.45†
ESR, mm/hour	NA	14.0 ~ 11.8	17.0 ~ 16.5‡	0.42§
RADAI	NA	2.6 ~ 1.6	2.6 ~ 1.7‡	0.43¶
Hand pain (RADAI)	NA	1.0 ~ 0.95	0.8 ~ 0.97‡	0.57†
HAQ score	NA	1.3 ~ 0.6	1.4 ~ 0.6‡	0.42¶
General health (HAQ), median (IQR)	NA	7 (5–8)	6 (5–9)‡	~0.55†
JAM, median (IQR)#	NA	2 (1–3)	1 (1–3)‡	0.38§
Grip strength, median (IQR)#	NA	16 (6–24.5)	13 (7–26)‡	~0.63†
ROM wrist flexion#	NA	48.2 ~ 26.1	57.6 ~ 23.1‡	0.03
ROM wrist extension#	NA	36.3 ~ 17.7	43.9 ~ 19.9‡	~0.05

* Values are the mean ~ SD unless otherwise indicated. RA ~ rheumatoid arthritis; D-JPBA-S (R) ~ German version of the revised Joint Protection Behavior Assessment short form; IQR ~ interquartile range; NA ~ not applicable; NM ~ not measured; DMARDs ~ disease-modifying antirheumatic drugs; NSAIDs ~ nonsteroidal antiinflammatory drugs; DAS28 ~ Disease Activity Score in 28 joints; ESR ~ erythrocyte sedimentation rate; RADAI ~ Rheumatoid Arthritis Disease Activity Index; HAQ ~ Health Assessment Questionnaire; JAM ~ Joint Alignment and Motion scale; ROM ~ range of motion.

† P ~ 0.0001; ‡ No significant change between baseline and 3 months; § P ~ 0.05; ¶ P ~ 0.001; # Of dominant hand.

Manual development

Face validity

The tasks contained in the UK version of the JPBA-S were checked for cultural applicability because of potential differences in equipment used in Switzerland. Therefore, "putting in an electric plug" was removed. This is not a physically difficult task for Swiss patients with RA due to a different plug design. This task was replaced by "opening a milk pack," a convenient alternative that applies several JP principles and is frequently used in JP education. Filling, carrying, and pouring a kettle tasks were replaced with holding, carrying, and pouring a pan (optionally an electric kettle) because saucepans are more commonly used in Switzer-land to boil water. We anticipated that both men and women performed all 10 tasks as routine daily activities. To determine face validity, JP literature and the UK JPBA manual were reviewed to identify which JP principles were being applied during task performance (13). Several principles can be applied to

each task depending on method of performance. There are some differences in the UK JPBA-S because some tasks are performed differently in Switzerland (Table 2).

Table 2. Face and content validity of the D-JPBA-S*

	Joint protection principles face validity†				
D-JPBA-S tasks	**1**	**2**	**3**	**4**	**5**
Turn on water tap	√	√	√	√	√
Hold pan	√	√			√
Turn off water tap	√	√	√	√	√
Carry full pan	√	√			√
Open coffee jar	√	√		√	√
Close coffee jar	√	√		√	√
Pour hot water into cups	√	√	√		√
Open milk pack‡	√				√
Hold milk pack to pour milk	√	√		√	√
Carry full cup(s)		√	√		√

* D-JPBA-S ~ German version of the Joint Protection Behavior Assessment short form. ~ ~ joint protection principle fulfilled. † 1 ~ reducing effort by using aids, using assistive devices, and avoiding lifting, as well as good organization of workplace; 2 ~ distributing load over several joints; 3 ~ using joints in stable positions; 4 ~ use of strongest, largest (proximal) joints; 5 ~ avoiding positions of deformity. ‡ Omitted after Rasch analysis.

Content validity

All methods of performing the 10 tasks were described in behavioral codes. These codes either described normal hand use (i.e., as performed by healthy individuals) or hand use consistent with joint protective adaptation in patients with RA. We translated all codes of the selected tasks from the UK JPBA-S and added new codes found in German leaflets or books about JP, reported by experienced rheumatology OTs, and identified in the video recordings of individuals with and without RA. In total, 91 behavioral descriptions were generated for the 10 tasks, between 6 and 11 for each. A draft manual containing these descriptions (illustrated with photographs to en-sure understanding) was developed and sent to 8 OT experts. They were asked individually to score each code as a correct, partially correct, or incorrect JP behavior for patients with mild to moderate RA with wrist and hand involvement but without severe finger, hand, elbow, or shoulder deformities, because these can lead to difficulty performing common JP methods and require more idiosyncratic solutions.

Final scores allocated to the behavioral codes were based on the preliminary decision that consensus about being a correct or incorrect method by at least 6 of the 8 expert OTs was necessary. Descriptions that did not achieve this level of consensus were scored as partially correct. The manual was used as reference for assessing the video recordings.

Video recordings and additional measures

Video recordings were completed in kitchen facilities of the University Hospital Zurich. Participants were asked to use the same styles of faucets, containers for boiling water, milk packs, and assistive devices they normally used to ensure the assessment situation was as similar as possible to their home. All utensils were heavy enough to offer sufficient resistance to require a JP response from participants with RA. Participants were asked to make 2 cups of coffee in the same sequence and manner as they would normally do at home. They were kept unaware of the true purpose of the video recordings to reduce socially desirable responses. They were informed that the video camera would only focus on their hands and not their faces to preserve anonymity. Light conversation continued during the video recording to distract participants from consciously paying attention to their hand movements. The assessment was repeated after 3 months. Video recordings were transferred to Pinnacle Instant CD/DVD 8.0 software (Pinnacle Systems, Mountain View, CA) and were edited on compact discs for assessments.

The following parameters were measured for patients with RA: physical functional ability was assessed using the Hochberg functional classes (18) and the Health Assessment Questionnaire (HAQ), a disease-specific self-administered 20-item questionnaire (19); self-perceived disease activity and typical RA symptoms such as pain and morning stiffness were assessed using the RADAI, a self-administered 5-item questionnaire (20); general health status was assessed using a 10-cm visual analog scale with the end points bad and excellent; impairment of the dominant hand was measured using a goniometer (for active wrist joint range of motion), the Joint Alignment and Motion Scale (for finger and wrist joint deformity) (21), and a Jamar hand dynamometer (Lafayette Instrument Company, Lafayette, IN) (for grip strength) (22); and disease activity was assessed using the DAS28, calculated from the results of a 28 tender joint count, a 28 swollen joint count, and erythrocyte sedimentation rate (23).

Assessment procedures

Discriminant validity

Assessments were performed with patients with RA and healthy individuals to determine if their behaviors differed regarding JP. *Cross-sectional validity.* JP behavior within the RA group was correlated with functional impairment (assessed with the HAQ) and hand pain (assessed with RADAI pain items).

Reliability assessments. Four OTs and 2 PTs independently assessed JP performances of 10 randomly selected patients with RA and all 10 healthy participants (interrater reliability). Two random duplicate video recordings of 2 patients (patients A and B) were included to determine intrarater reliability. Raters were blinded to the presence of duplicates. These duplicates were reassessed 4 weeks later by all raters, thus simulating the clinical situation of OTs reassessing their patients. One of the 6 raters assessed the

video recordings of all 23 patients at both time points. The raters were asked to strictly follow the manual to minimize observer drift while assessing.

Rasch analysis

The Rasch model reverses the traditional view of the data-model relationship, i.e., data must fit the model, meaning that the observed frequencies should not differ too much from expected values (24). Rasch model theory states that response probabilities change as a function of participant ability and item difficulty (expressed as logits), i.e., the probability that a per-son with a logit score of 1.0 will pass an item with a difficulty of 1.0 logit is 50%, but the probability that he or she will pass an item with a difficulty ~1 logit or ~1 logit is ~50% or ~50%, respectively. Rasch models provide various error estimates and fit statistics, especially for testing unidimensionality (i.e., if indeed a single dominant trait is being measured) and scale additivity (i.e., the probability that difficult items are only passed by high-scoring participants whereas less-able participants only pass easier items). This particularly allows gathering of further evidence of the construct validity of a measure. Each item and person is calibrated to provide a difficulty estimate and an ability estimate, respectively, of the location on an abstract linear continuum from less to more, thus providing an equal interval scale representing the variable, in this case, JP behavior.

Statistical analysis

The Rasch Partial Credit Model was applied (25), because the steps (thresholds) between the adjacent scores (incorrect/partially correct/correct ~ 0/1/2) might be different across tasks. The raters were also accounted for as a person factor to control for bias. Complete data for all 120 ratings were available, and 90 ratings without extreme scores (0 points) (26) were analyzed for construct validity. Individual item fit to the model was examined with ~ at 5%. To reach overall probability in the 10-item D-JPBA-S testing, Bonferroni correction was used throughout and therefore the significance values were set at 0.005 (27).

All reliability tests were performed for the original D - JPBA-S (D-JPBA-S [O]; i.e., using ordinal raw scores for all 10 tasks) and the revised D-JPBA-S (D-JPBA-S [R]; i.e., using linear data of all tasks fitting the Rasch model). Intraclass correlation coefficients (ICCs) were calculated using 2-way random-effects models and consistency definition for all reliability measures. The ICC provides information on the ability of ~2 observers to differentiate between subjects. For interrater reliability, we expected an $^{ICC}2,6$ of ~0.80. For intrarater reliability, we expected an $^{ICC}2,1$ of ~0.80. To evaluate real changes in clinical practice and research, a test–retest change determined by a specific measurement must be at least the smallest detect-able difference (SDD), which is calculated as follows: SDD ~ 1.96 ~ ~2SEM^2, where SEM (standard error of measurement) is SD ~ ~(1 ~ r) and r is the reliability coefficient (28). Pearson's correlation coefficients were calculated to measure associations between the D-JPBA-S (R) data and disease-specific

data; Mann-Whitney U test was used to test differences between healthy individuals and patients with RA. Rasch analysis was performed using the Rasch Unidimensional Measurement Model RUMM2020 software package (RUMM Laboratory, Duncraig, Western Australia). All ICC calculations and statistical testing were performed using the SPSS software, version 12.0 (SPSS, Chicago, IL).

Results

Content validity of the D-JPBA-S

Agreement on the scores between ~6 of the 8 OT experts was achieved for 53 of the 91 behavioral descriptions (58%), with 22 descriptions scored as correct and 31 as incorrect. There was insufficient agreement on 38 descriptions, which were therefore scored as partially correct.

Construct validity of the D-JPBA-S using Rasch analysis.

Examining fit of the 10 D-JPBA-S tasks to the Rasch model revealed that task 1 (turn on tap), task 2 (hold pan), and task 4 (carry pan) were significant at P ~ 0.005 (chi-square probabilities, all after Bonferroni correction), i.e., the observed values of these 3 tasks were significantly different from the expected values and therefore did not fit the model (Table 3). Additionally, the thresholds for task 2 (hold pan), task 4 (carry pan), and task 8 (open milk pack) were disordered, i.e., their scoring categories were not progressing in a logical order. It can be expected that as a person's ability increases, it will be more likely for him or her to obtain a higher score; however, in the case of disordered thresholds, the items do not work in this way. Subsequently, scoring categories 1 and 2 were collapsed for the 3 disordered tasks, resulting in dichotomous data of 0 (for incorrect and partially correct) and 1 (correct) for tasks 2, 4, and 8. After rescoring, task 8 (open milk pack) still did not fit the model at the 0.5% significance level. No 8 was removed, resulting in a model fitting all remaining items, i.e., a valid assessment was obtained (Table 3).

Table 3. Individual item fit of the D-JPBA-S (R)*

	Initial values unchanged			After rescoring tasks 2, 4, 8			After removing task 8		
			Chi-square			Chi-square			Chi-square
	Item	Values	probability	Item	values	probability	Item	Values	probability
Task 1	Turn on tap	12.34	0.002†	Turn on tap	1.04	0.569	Turn off tap	0.373	0.830
Task 2	Hold pan	20.18	0.000†	Carry pan	1.59	0.452	Carry pan	0.418	0.812
Task 3	Turn off tap	1.11	0.574	Hold pan	1.60	0.450	Carry cups	3.500	0.174
Task 4	Carry pan	11.51	0.003†	Turn off tap	2.00	0.369	Pour water	5.322	0.070
Task 5	Open jar	6.45	0.040	Pour water	3.21	0.201	Turn on tap	5.598	0.060
Task 6	Close jar	8.50	0.014	Carry cups	3.78	0.151	Hold pan	6.707	0.035
Task 7	Pour water	7.00	0.030	Open jar	9.52	0.009	Pour milk	6.799	0.033
Task 8	Open milk	10.73	0.005	Pour milk	9.93	0.007	Close jar	6.995	0.030
Task 9	Pour milk	8.53	0.014	Close jar	10.05	0.007	Open jar	10.670	0.005
Task 10	Carry cups	4.11	0.128	Open milk	27.00	0.000†			

* Initial values are presented in serial order; values after rescoring and after removing nonfitting tasks are presented in chi-square probability order.

D-JPBA-S (R) ~ German version of the revised Joint Protection Behavior Assessment short form.

† Significant at *P* ~ 0.005 (after Bonferroni correction).

Test-of-fit statistics demonstrated a mean ~ SD item location (i.e., difficulty) of 0 ~ 2.2 and a mean ~ SD person location (i.e., ability) of ~3.4 ~ 1.3, implying that participants' ability was too low in relation to the items' difficulty (Figure 1).

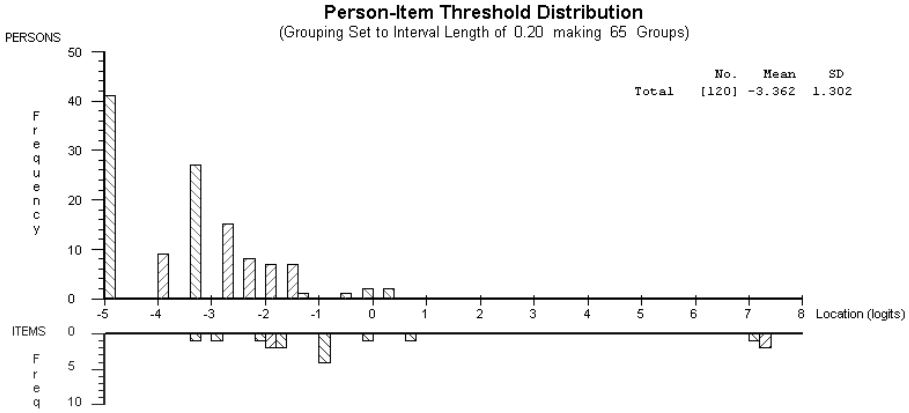

Figure 1. Person/item threshold-targeting graph of the German version of the revised Joint Protection Behavior Assessment short form ([ratings of] persons: n ~ 120; items: n ~ 9). Locations of persons (~ person abilities) and of each item threshold (1 thresh-old for the dichotomous tasks 2 and 4, 2 thresholds for all other polytomous items) on the interval scale, representing the measure of joint protection behavior. Easiest item thresholds are from incorrect to partially correct for the tasks "pour milk" and "turn on tap," with mean logits of ~3.3 and ~2.8, respectively (on the left). Most difficult item thresholds are from partially correct to correct for the tasks "turn on tap," "open jar," and "pour water," with mean logits of 7.2 and 7.4, respectively (on the far right).

The formal test of invariance (item–trait interaction) revealed a total item chi-square of 46.4 *(P* ~ 0.001), indicating significant deviation between the observed data and what was expected from the model at group level. Reliability indices were 0.79 (person separation index, indicative of the power of the D-JPBA-S to discriminate between respondents) and 0.77 (Cronbach's alpha). Person logits of the D-JPBA-S (R) were transformed into an arbitrarily chosen 0–18 interval scale for further calculations.

Reliability

The demographic characteristics of the healthy participants and those with RA were comparable (Table 1). Mean values of the 6 raters' scorings were between 3.5 and 5.4 on the D-JPBA-S (R) scale and differences were not significant (Kruskal-Wallis H test *P* ~ 0.50).

Interrater reliability

Overall interrater reliability for the D-JPBA-S (O) was 0.79 (95% confidence interval [95% CI] 0.74–0.85), ranging between 0.84 (95% CI 0.76–0.91) and 0.70 (95% CI 0.54–0.82) for each pair of raters. Reliability values slightly decreased when calculated for the D-JPBA-S (R), being 0.77 (95% CI 0.70–0.83) across all raters and ranging between 0.84 (95% CI 0.75–0.90) and 0.65 (95% CI 0.47–0.80) for each pair of raters.

Intrarater reliability

The intrarater reliability of each rater was generally higher in the assessments of time point 1 than of time point 2, which was true for both patient A and patient B. The intrarater agreement range for patient A was 80–100% (mean ~ SD 95% ~ 8.4%) at time point 1 and 50–100% (mean ~ SD 75% ~ 20.7%) at time point 2; for patient B, values were 100% at time point 1 and 70– 100% (mean ~ SD 90% ~ 11.7%) at time point 2. Results were the same for the D-JPBA-S (O) and D-JPBA-S (R). Because raters scored this sample within a very restricted range, resulting in low variability, ICC calculations were not applicable.

Test–retest reliability

Patients repeated the kitchen activity after a mean ~ SD of ~11 ~ 2.5 weeks. ICCs were 0.65 (95% CI 0.27–0.87) for the D-JPBA-S (O) and 0.71 (95% CI 0.31–0.88) for the D-JPBA-S (R). On the 18-point linear scale, the median D-JPBA-S (R) score on test 1 was 7.7 points (interquartile range [IQR] 3.4–9.3) and on test 2 was 5.8 (IQR 3.35–7.7). Score changes over the 2 tests were between 0 and 12.2, and the mean ~ SD score change was 1.1 ~ 3.7 points. SDD was 5.5 points on the linear scale.

Disease-related factors and JP behavior

Calculations in this section were performed with D-JPBA-S (R) linear data. The D-JPBA-S (R) scores of the RA participants were negatively correlated with grip strength (r ~ –

0.63, *P* ~ 0.001). Correlations with all other disease-related factors were significantly positive. No correlation was found with range of motion at the wrist joint (Table 1).

Discriminant validity

The D-JPBA-S (R) discriminated significantly (Mann-Whitney U test; z ~ ~8.215, *P* ~ 0.0001) between healthy individuals and those with RA regarding JP behavior. The median score was 0 points (IQR 0–2.9) for healthy individuals and 6.5 (IQR 5.0–9.0) for those with RA (Table 1).

Cross-sectional validity

Pearson's correlation coefficient of JP behavior with functional impairments in patients with RA (measured with the D-JPBA-S [R]) was 0.42 *(P* ~ 0.0001) and correlation with hand pain was 0.57 *(P* ~ 0.0001) (Table 1).

Discussion

The final version of the D-JPBA-S, as obtained with Rasch modeling, i.e., consisting of 9 valid tasks, is suitable for measuring JP behavior. Traditionally, analysis of outcome data focused on summing and dividing raw scores that are ordinal; however, calculations with such data may not be justified. Performing Rasch analysis is far more than a conceptual issue and its results had practical implications for the construct of the D-JBPA-S. For task 2 (hold pan) and task 4 (carry pan), it was difficult to assess whether the assisting hand held the pan's weight (scored as correct) or was only supporting (partially correct). Therefore, raters may have randomly assigned scores, not perceiving a substantial difference. Collapsing incorrect and partially correct scores in this case is advantageous without losing information. Task 8 (open milk pack) was not an appropriate item because it did not discriminate between JP performance of healthy individuals and patients with RA. Both groups had trouble opening the milk pack, irrespective of health status or awareness of protecting joints.

Reliability calculations were based on linear scores of the D-JPBA-S (R) as well as on summed raw scores of the D-JPBA-S (O). Reliability for the D-JPBA-S (R) was slightly lower because one item was deleted. Because the D-JPBA-S will be used as an evaluative assessment, it is of no use to collapse all ordered polytomous scales into dichotomous scales to raise reliability, as this would diminish precision.

More important is the accurate measurement of change between 2 time points by transforming raw scores into linear data because raw score changes might be misinterpreted. Every linear difference (test 2 minus test 1) corresponds to a range of raw score differences, which differ depending on test 1 initial status (29). Test–retest reliability integrates variability within the patients' group and within the rater, i.e., a change of the rater's assessment might reasonably be due to different JP performances of some patients.

The period between test and retest may appear to be long. However, we anticipated that noticeable changes in habitual JP behavior could occur due to unpredictable daily pain changes. This was also identified in an earlier study (8) and was confirmed in our video recordings. Different JP performances due to large pain changes in (few) individuals explain our SDD of 5.5 points (~30% of the total range), even though most patients were in a stable condition and the overall correlation between pain and JP behavior was moderate. Although the usually low initial scores promote large improvements, it might be difficult to detect true differences in individual patients when disease-dependent changes interfere with real changes. The discrepancy between difficulty of items and per-sons' ability also illustrates that individuals without RA have no reason to perform JP and that individuals with RA perform less JP than might be expected because they do not recall JP instructions. Participants with RA stated that the effective drug treatment had lowered their perceived need and their motivation to apply JP during daily activities. However, difficulty levels of items are very different and there is a large gap within the scale. Further development of the scale should take this into account, e.g., by weighting the items, to improve its appropriateness (30).

The manual describes the application of the D-JPBA-S and all possible JP methods and is illustrated with pictures. This is essential to ensure reliable assessments. The decision about how much agreement was required to as-sign the scores correct, partially correct, and incorrect for the manual was arbitrary. Requiring a higher level of agreement for correct/incorrect scores means more partially correct scores. Persons with RA often show partially correct behavior, having been told about JP behavior without fully understanding the principles behind it or having developed their own idiosyncratic methods, and therefore the potential for improvement is quite substantial. For example, a common, easy-to-learn principle is to work bilaterally.

Intrarater agreement between time points 1 and 2 was almost 100%. Raters may have recognized the individuals and, being convinced of their first scorings, persisted in their scores. Intrarater agreement after 4 weeks was considerably lower for some raters, suggesting that they per-formed assessments in a more unbiased and critical fashion. This second value might therefore be more accurate and nearer to the reality of clinical practice in which assessments are repeated some weeks later in the course of OT intervention.

Our patients may be considered representative of the RA population on relevant characteristics such as sex, age, and disease severity, and there is evidence that measurement constructs are stable across samples from a common population regardless of sample size (31). This validation provided the prerequisites for using the D-JPBA-S in research. Further analysis (e.g., using generalizability theory) is needed to allow estimations of change on an individual patient level.

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References

1. Scott DL. Prognosis and clinical course. In: St. Clair EW, Pisetsky DS, Haynes BF, editors. Rheumatoid arthritis. 1st ed. Philadelphia: Lippincott Williams & Wilkins; 2004. p. 26–41.
2. Stenstrom CH. Physical therapy. In: St. Clair EW, Pisetsky DS, Haynes BF, editors. Rheumatoid arthritis. 1st ed. Philadelphia: Lippincott Williams & Wilkins; 2004. p. 425–30.
3. Backman CL, Fairleigh A, Kuchta G. Occupational therapy. In: St. Clair EW, Pisetsky DS, Haynes BF, editors. Rheumatoid arthritis. 1st ed. Philadelphia: Lippincott Williams & Wilkins; 2004. p. 431–9.
4. Eberhardt KB, Fex E. Functional impairment and disability in early rheumatoid arthritis: development over 5 years. J Rheumatol 1995;22:1037–42.
5. Mody GM, Meyers OL, Reinach SG. Handedness and deformities, radiographic changes, and function of the hand in rheumatoid arthritis. Ann Rheum Dis 1989;48:104–7.
6. Cordery J, Rocchi M. Joint protection and fatigue management. In: Melvin J, Jensen G, editors. Rheumatologic rehabilitation: assessment and management. Bethesda: The American Occupational Therapy Association, Inc; 1998. p. 2 79–322.
7. Nordenskiold U, Grimby G, Dahlin-Ivanoff S. Questionnaire to evaluate the effects of assistive devices and altered working methods in women with rheumatoid arthritis. Clin Rheumatol 1998;17:6–16.
8. Hammond A. Joint protection behavior in patients with rheumatoid arthritis following an education program: a pilot study. Arthritis Care Res 1994;7:5–9.
9. Hammond A, Lincoln N, Sutcliffe L. A crossover trial evaluating an educational-behavioural joint protection programme for people with rheumatoid arthritis. Patient Educ Couns 1999;37:19–32.
10. Hammond A, Freeman K. One-year outcomes of a randomized controlled trial of an educational-behavioural joint protection programme for people with rheumatoid arthritis. Rheumatology (Oxford) 2001;40:1044–51.
11. Hammond A, Freeman K. The long-term outcomes from a randomized controlled trial of an educational-behavioural joint protection programme for people with rheumatoid arthritis. Clin Rehabil 2004;18:520 –8
12. Freeman K, Hammond A, Lincoln NB. Use of cognitive-behavioral arthritis education programmes in newly diagnosed rheumatoid arthritis. Clin Rehabil 2002;16:828–36.
13. Hammond A, Lincoln N. Development of the Joint Protection Behavior Assessment. Arthritis Care Res 1999;12:200–7.
14. Klompenhouwer PJ, Lysack C, Dijkers M, Hammond A. The Joint Protection Behavior Assessment: a reliability study. Am J Occup Ther 2000;54:516–24.
15. Hammond A, Lincoln N. The effect of a joint protection education programme for people with rheumatoid arthritis. Clin Rehabil 1999;13:392–400.
16. Hammond A, Jeffreson P, Jones N, Gallagher J, Jones T. Clinical applicability of an educational-behavioral joint protection programme for people with rheumatoid arthritis. Br J Occup Ther 2002;65:405–12.

17. Arnett FC, Edworthy SM, Bloch DA, McShane DJ, Fries JF, Cooper NS, et al. The American Rheumatism Association 1987 revised criteria for the classification of rheumatoid arthritis. Arthritis Rheum 1988;31:315–24.
18. Hochberg MC, Chang RW, Dwosh I, Lindsey S, Pincus T, Wolfe F. The American College of Rheumatology 1991 revised criteria for the classification of global functional status in rheumatoid arthritis. Arthritis Rheum 1992;35 :498–502.
19. Bruhlmann P, Stucki G, Michel BA. Evaluation of a German version of the physical dimension of the Health Assessment Questionnaire in patients with rheumatoid arthritis. J Rheumatol 1994;21:1245–9.
20. Fransen J, Langenegger T, Michel BA, Stucki G. Feasibility and validity of the RADAI, a self-administered Rheumatoid Arthritis Disease Activity Index. Rheumatology (Oxford) 2000;39:321–7.
21. Spiegel TM, Spiegel JS, Paulus HE. The joint alignment and motion scale: a simple measure of joint deformity in patients with rheumatoid arthritis. J Rheumatol 1987;14:887–92.
22. Jones E, Hanly JG, Mooney R, Rand LL, Spurway PM, East-wood BJ, et al. Strength and function in the normal and rheumatoid hand. J Rheumatol 1991;18:1313–8.
23. Prevoo ML, van 't Hof MA, Kuper HH, van Leeuwen MA, van de Putte LB, van Riel PL. Modified disease activity scores that include twenty-eight-joint counts: development and validation in a prospective longitudinal study of patients with rheumatoid arthritis. Arthritis Rheum 1995;38:44–8.
24. Rasch G. Probabilistic models for some intelligence and attainment tests. Expanded ed. Chicago: University of Chicago Press; 1980.
25. Tesio L. Measuring behaviours and perceptions: Rasch analysis as a tool for rehabilitation research [published erratum appears in J Rehabil Med 2003;35:294]. J Rehabil Med 2003; 35:105–15.
26. Betemps EJ, Smith R, Baker DG, Rounds-Kugler BA. Measurement precision of the clinician administered PTSD scale (CAPS): a RASCH model analysis. J Applied Meas 2003;4:59– 69.
27. Gross Portney L, Watkins MP. Foundations of clinical research: applications to practice. Norwalk (CT): Appleton & Lange; 1993. p. 406–7.
28. Guyatt G, Walter S, Norman G. Measuring change over time: assessing the usefulness of evaluative instruments. Chronic Dis 1987;40:171–8.
29. Bezruczko N. Raw score nonlinearity obscures growth. Rasch Meas Trans URL: http://www.-rasch.org/rmt/rmt182a.htm.
30. Tennant A, Hillman M, Fear J, Pickering A, Chamberlain MA. Are we making the most of the Stanford Health Assessment Questionnaire? Br J Rheumatol 1996;35:5 74–8.
31. Fisher WP Jr. Physical disability construct convergence across instruments: towards a universal metric. J Outcome Meas 1997;1:87–113.

Chapter 4

Perceived benefits and barriers of joint protection among people with rheumatoid arthritis and occupational therapists. A mixed method study

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Abstract

Background: Deciding whether to perform a health behaviour or not is an active decision making process impacting on current and future behaviour, which can be influenced by both the beliefs of patients and their health care professionals. The aim of this study was to explore people with rheumatoid arthritis' (RA) and occupational therapists' (OTs) perceptions of the benefits of and barriers to performing joint protection (JP).

Methods: A mixed methods design was used. Questionnaires applied a theoretical framework of key themes to assess the relevance of JP benefits and barriers to both people with RA and OTs. Focused interviews with people with RA then enabled data triangulation. Investigator triangulation was used to check the validity of data interpretation.

Findings: Ten people with RA and nine OTs participated. From the questionnaires, both groups agreed highly relevant key themes for JP benefits were *'physical well-being', 'potential benefit'*, and *'personal control.'* In contrast, the three key themes for JP barriers: *'negative attitude of others'*, *'negative impact on others'* and *'taking time from other things'* were relevant for the majority of the OTs but not patients. The interviews enabled understanding the meaning behind people with RA's ratings, particularly their differences to OTs. People with RA explained JP benefits and disease acceptance had altered some initial barriers into perceived benefits over time.

Conclusions: Emphasizing benefits and identifying individually relevant barriers could be an important communication strategy for OTs in understanding patients' rationale for adopting or not JP methods.

Key words: occupational therapy, joint protection behaviour, Transtheoretical Model, decision making

Introduction

Behaviour change in a chronic disease

The treatment of chronic diseases, such as rheumatoid arthritis (RA), requires patients to make multiple behavioural changes. This may include the management of symptoms, treatment, the physical and psychosocial consequences of the disease and lifestyle changes (Newman et al. 2004). Behavioural changes and adhering with treatment are not 'events' but changing states dependent on complex interactions, including attitudes to illness, expectations of health, previous experiences of the illness and social pressures (Price 2008).

Joint protection education

Joint protection (JP) is a self-management approach for coping with pain and functional limitations in order to improve daily task and role performance. It includes the application of alternative working methods, balancing activity and rest and use of assistive devices. In both the short and long-term increased use of JP significantly improves function and reduces pain, given that psycho-educational teaching methods are applied (Hammond and Freeman 2001, Hammond and Freeman 2004). However, whatever the educational approach used, not all patients change as a result of JP education. Gaining insight into the complex beliefs influencing whether people decide to change or not could help occupational therapists (OTs) improve their quality of JP education by addressing issues of personal relevance to patients.

Decisional balance and the Transtheoretical Model (TTM)

Decision making is considered a critical process in changing behaviours or adhering to new behaviours. Originally Janis and Mann's theory of medical decision making suggested a scheme for representing cognitive and motivational aspects of decision making (Janis and Mann 1968, Janis and Mann 1977). This gain-versus-loss model included eight dimensions. Four were benefits: gains for self and others and approval from self and others. Four were costs: losses for self and others and disapproval from self and others. However, later research has consistently found just two categories: the Pros (benefits) and Cons (barriers) towards a behaviour (Prochaska 2008). This concept of decision making was integrated into the Transtheoretical Model (TTM) which conceptualises behavioural change as a cyclical process through five stages of readiness to change: precontemplation- contemplation- preparation- action- maintenance (Prochaska et al. 1992). The underlying relationships between these stages of change and the variables of perceived benefits and perceived barriers have been found to be consistent across a multitude of behaviours (Prochaska et al. 1994). Thus in precontemplation, the individual is not intending to take action and not ready to change behaviour: perceived barriers outweigh perceived benefits. In contemplation, the individual is intending to take action within the next six months. The person is ambivalent about changing, perceiving benefits and barriers as equally important. At each subsequent stage from preparation to maintenance, perceived benefits increase whilst perceived barriers decrease. The

longer a person performs a (new) behaviour, the more pronounced this difference becomes. Consequently, the scope and quality of an individual's decision making may be extremely relevant in understanding both their current behaviour as well as their attempts to change behaviour (Marcus et al. 1992, Prochaska 2008).

The application of the TTM to joint protection (JP) education

The TTM can be applied to JP education to help hypothesise why people may or may not choose to use JP. For example, a person referred for JP education from a Rheumatology clinic, having been persuaded to be referred with insufficient explanation, is potentially more likely to be in the precontemplation or contemplation stage and not yet ready to change JP behaviour. (S)he may be underinformed, unmotivated or even resistant. For whatever reason, action-oriented JP education is less likely to succeed. A motivational intervention may be more beneficial, identifying and working through the person's perceived benefits and barriers and raising their confidence (self-efficacy) in performing JP. In contrast, those in the preparation and action stages are ideal for action-oriented JP-education, e.g. mutually developing action-plans and home programmes to enable change. They have probably already discussed JP with their doctor or rheumatology nurse, read information and/or tried some self-help approaches and perceive more benefits than barriers in changing behaviour. People in the maintenance stage have been applying the new behaviour for at least 6 months. In TTM theory terms, the new behaviour is being sufficiently performed to alter disease effects. In terms of JP behaviour, people in the action and maintenance stages are using JP methods appropriately in many tasks to reduce pain, fatigue and joint stress during activities (Hammond and Freeman 2004). They perceive sufficient benefits for continuing JP behaviour most of the time, although they may need to work at preventing relapse in difficult situations when they are tempted to give up or are less confident in continuing with JP. People in the maintenance stage have made permanent changes in behaviour, many of which are unconsciously integrated into their routines and lifestyle. Understanding people with RA's beliefs about benefits and barriers of JP could help in applying stage-matched JP education, which could potentially improve both effectiveness and cost-effectiveness of the intervention (Hammond and Freeman 2001, Hammond and Freeman 2004).

The influence of beliefs of patients and health professionals on health behaviours

Previous studies have found that beliefs of both patients and health professionals influence use of health behaviours. For example, for people with RA perceived benefits, positive attitudes and having no concerns related to negative or side effects were important determinants of wearing wrist working splints (Agnew 1995, Veehof et al. 2008). Barriers to using JP have been identified as: not personally perceiving the relevance of JP as "my hands are not that bad yet"; difficulty recalling information; finding the movements initially more awkward and slow; and difficulty changing the habits of a lifetime (Hammond and Lincoln 1999). Beliefs and cognitions health professionals hold towards a specific behaviour also influence how much they motivate people to change

and whether people correspondingly then adhere to that treatment (Iversen et al. 2004). Thus it is important to understand perceptions of JP in both people with RA and occupational therapists (OTs) to enable therapists to devise effective communication strategies supporting behavioural change. The aim of this study was therefore to evaluate people with RA and OTs perceptions of the benefits of and barriers to using joint protection.

Methods

Design

A mixed methods design (Creswell 1995) was applied in this study with simultaneous use of qualitative and quantitative approaches. This design enables gaining different perspectives from the data, known as triangulation (Dezin 1978). Questionnaires provided quantitative profiles of the perceptions of people with RA and therapists. Semi-structured interviews with RA participants complemented these so that detailed qualitative data enabled a closer investigation of their perceptions, beliefs and experiences.

Participants

A convenience sample of German speaking people, diagnosed with RA according to ACR guidelines (Arnett FC 1988), was recruited by the treating rheumatologist at the outpatient facility of a University Hospital's rheumatology department. Patients were invited to participate if they: were in ACR functional class ll (able to perform usual self-care and vocational activities, but limited in avocational activities), lll (able to perform usual self-care activities, but limited in vocational and avocational activities) or lV (limited ability to perform usual self-care, vocational, and avocational activities) (Hochberg et al. 1992); had previously received JP education; and reported continuing using hand JP methods.

A convenience sample of 10 OTs from five different rheumatology departments, experienced in treating people with RA and regularly teaching JP, were invited to participate. JP education in Switzerland usually consists of oral and written information about RA and JP principles (Cordery and Rocchi 1998); demonstrations and supervised practice of hand JP methods, mostly in a kitchen activity, and demonstration of appropriate assistive devices, provided in a one-to-one setting for up to three to four hours over several sessions. Psycho-educational methods are infrequently used.

Ethical approval

The Local Research Ethics Committee approved the study protocol and all patients provided informed written consent.

Item generation and development of the questionnaire

Five experienced Rheumatology OTs (not participating in the data collection phase) helped compose the questionnaire of perceived benefits and barriers to using hand JP in RA. Items were generated from their clinical experience, reviewing the contents of JP theoretical literature (Cordery and Rocchi 1998) and TTM decisional balance question-

naires for other self-management behaviours, i.e. prevention of back pain (Basler et al. 1998) and physical activity (Nigg et al. 1998). To determine face validity of the questionnaire, a "Decisional Balance Sheet for Incentives," as suggested by Janis and Mann, was constructed and items were allocated to identify whether they adequately represented the benefits and barriers of: gains or losses for self (+self/-self), gains or losses for significant others (+oth/-oth), self-approval or disapproval (+aps/-aps), approval or disapproval by significant others (+apo/-apo) (Janis and Mann 1968, 1977).

During the development phase, in order to construct the theoretical framework facilitating later quantitative and qualitative analysis, the questionnaire benefit and barrier items were conceptually allocated to key themes through consensus by two researchers (KN, AH). The 25 benefit items were grouped into: *psychological well-being* (4 items), *physical well-being* (8 items), *potential benefit* (4 items), *self-acceptance* (2 items), *altruism* (1 item), *personal control* (5 items) and *self-image* (1 item). The 20 barrier items were grouped into: *negative impact on self-image* (6 items), *negative attitude of others* (3 items), *negative impact on others* (1 item), *taking time from other things* (3 items) and *difficulties/ effort* (7 items). However, these benefit/barrier groupings were not disclosed to the patients and OTs and items were presented in a disordered sequence to avoid biasing their answers. A dichotomous rating scale (*0=not relevant,* 1=*relevant*) for items was selected to reduce the cognitive response burden to participants (Molenaar 1982).

Procedure

The questionnaires were used to quantitatively investigate the relevance of benefits of and barriers to JP as perceived by people with RA and OTs. For people with RA, the questionnaire formed the basis of a focused interview (Merton and Kendell 1979). They were initially asked '*what does the term joint protection mean to you?"* as an introduction to discussing the questionnaire items. They were then asked to rate whether each benefit and barrier item in the questionnaire was relevant or not to perform JP. Each statement was read to them, using the same root statement for each item *'If I perform joint protection methods regularly then. . . .* ' For each item, they were asked to share their personal interpretation of the item and any personal experiences by freely associating and thinking aloud. Their rating and comments were noted verbatim by the interviewer (KN) and read to the patients to check correct recording.

Additionally, demographic and clinical characteristics of the patients were recorded, including whether rheumatoid factor positive, disease activity (using the DAS28) (Prevoo et al. 1995), current drug therapy and functional disability (German version of the Health Assessment Questionnaire, HAQ) (Brühlmann et al. 1994).

The same questionnaire was sent to the 10 experienced Rheumatology OTs, who were asked to rate if they considered each benefit or barrier item relevant or not for JP in RA. One week after the deadline, non-responders were reminded by telephone. Nine of the 10 OTs responded, with one unable to complete within the time given.

Data analysis

The analysis consisted of a parallel mixed analysis of quantitative and qualitative data (i.e. data source triangulation). Quantitative data from questionnaire ratings by RA participants and OTs were analyzed using descriptive statistics and Pearson's Chi-square tests to explore agreement between people with RA and OTs on each item's relevance, with $p \leq 0.05$ considered significant. SPSS version 16.0 (SPSS, Chicago, IL) was used.

Qualitative data from the RA participants' interviews were analysed by three researchers with different professional backgrounds, i.e. a physiotherapist (KN), an occupational therapist (AH) and a rheumatologist (AF) (i.e. investigator triangulation). Interpretative phenomenological analysis was applied to understand beliefs and perceptions. 'Phenomenological' indicates that statements are based on interviewees' underlying beliefs and cognitions (Smith et al. 1997). 'Interpretative' acknowledges that, although it is claimed that interviewees' answers represent their personal perceptions, the interpretation of the interview/transcript is determined by the researcher(s) (Smith et al. 1999).

The analysis process of the qualitative data was as follows:

a) RA participants' definitions and perceptions of JP: a list of items and common themes was generated. The final allocation of interview responses was performed by discussion between KN and AH and then reviewed by AF and RdB.

b) Responses to the benefit and barrier items: a two-round, Delphi-like procedure (Jones and Hunter 1995) among three researchers (KN, AH, AF) was performed. In the first round, all responses were independently allocated by the researchers either to the key themes of the theoretical framework identified during questionnaire development (e.g. physical well-being, personal control) or to emerging ones if appropriate. In the second round all researchers were informed of each others' first round allocations. Discussion about the rationale for allocation of statements occurred and was resolved by consensus.

Results

Participants: Characteristics of the RA participants' are presented in Table 1. They had established RA and their disease was well-controlled by medication as the average DAS score was 3.2 (DAS28 values <= 3.2 are regarded as representing low disease activity) (van Gestel et al. 1998). The OTs had on average 4.8 (range 2-10) years of experience with rheumatology patients.

Table 1: Demographic and clinical characteristics of patients (n=10)

Gender (male / female)	2 / 8
Age (yr), mean (SD)	58.40 (12.80)
Disease duration (yr), mean (SD)	13 (9.97)
ACR functional class, (no. participants in class I/II/III)	1/ 5 / 4
Rheumatoid factor (+) (no. patients)	10
Drug therapy (no. patients):	
DMARDs (including biologics)	10
Steroids	6
NSAIDs	4
Analgesics	1
DAS28, mean (SD)	3.2 (1.74)
HAQ, mean (SD)	1.28 (0.83)

ACR functional class = American College of Rheumatology classification criteria for functional status in Rheumatoid Arthritis (class I to IV); DMARDs = disease-modifying anti-rheumatic drugs; NSAIDs = non-steroidal anti-inflammatory drugs; DAS28 = Disease Activity Score in 28 joints; HAQ = Health Assessment Questionnaire (score range = 0-3)

A) Questionnaire ratings of patients and OTs

The relevance ratings of all benefit and barrier items by RA participants and OTs are presented in Table 2. Most benefits were relevant for the majority of both groups, i.e. at least six of the 10 RA participants and at least five of the nine OTs. The items within the themes *'physical well-being', 'potential benefit'*, and *'personal control'* were generally equally relevant for RA participants and OTs, with two significant overall disagreements between the groups. Three OTs did not rate the item *'would make me feel more confident'.* The items in the themes *'psychological well-being', 'self-acceptance'* and *'self-image'* were generally rated inconsistently relevant by RA participants and less relevant by OTs, again with two significant disagreements between the two groups.

In contrast to the benefit items, only three of the barrier items were relevant for the majority of people with RA: all related to the use of assistive devices. In contrast, only two barrier items were *not* relevant for the majority of OTs. There was significant disagreement in 9 of the 21 barrier items within the themes *'negative impact on self-image', 'negative attitude of others', 'negative impact on others' and 'taking time from other things'.* The barrier items of the theme '*difficulties/effort*' were moderately relevant for people with RA and OTs, but these were the only perceived barriers both groups agreed on.

Table 2: Benefits of and barriers to joint protection (answers to the root statement: 'If I perform/use joint protection methods regularly, then . . . ')

	Answers of RA participants (n=10)		Answers of occupational therapists (n=9)			Significance of difference in ratings between groups (X^2)
a) Benefits: rewards, benefits	Relevant	Not relevant	Relevant	Not relevant	No answer	p≤ 0.05
Physical well-being						
+self . . . I feel more comfortable with my body	8	2	8	0	1	0.60
+self . . . I sleep more soundly	4	6	5	1	3	0.50
+self . . . it is easier for me to perform routine physical tasks	10	0	7	0	2	0.12
+self . . . I can avoid pain	10	0	7	0	2	0.12
+self . . . I can reduce the pain that is present	10	0	7	0	2	0.12
+self . . . I can work /do housework with less pain	10	0	8	0	1	0.28
+self . . . I have less physical stress	8	2	7	1	1	0.91
+self . . . I have more strength	8	2	8	0	1	0.60
Psychological well-being						
+oth . . . I have more energy for my family and friends	3	7	7	2	0	0.04 *
+self . . . I feel less stressed	6	4	6	2	1	0.76
+self . . . it puts me in a better mood for the rest of the day	3	7	3	4	2	0.76
+self . . . it helps me have a more positive outlook on life	9	1	5	3	1	0.09
Potential benefit						
+self . . . I can prevent damage	10	0	7	0	2	0.12
+self . . . I have a higher quality of life	10	0	6	1	2	0.05 *
+self . . . I am more relaxed in the long-term	9	1	6	1	2	0.21
+apo . . . I save later health costs for the health care system	9	1	7	0	2	0.47
Personal control						
+self . . . would make me feel more confident	10	0	6		3	0.05 *
+self . . . I can actively contribute to my health	9	1	7	0	2	0.47
+self . . . I am conscious of actively doing something for my health	10	0	7	0	2	0.12
+self . . . I feel more independent from other people	10	0	8	0	1	0.28
+self . . . I take better care of my joints	10	0	8	0	1	0.28
Self-acceptance						

		Answers of RA participants (n=10)		Answers of occupational therapists (n=9)			Significance of difference in ratings between groups (X^2)
+aps	. . . I would feel good about myself if I kept my commitment to look after my joints regularly	10	0	5	1	3	0.09
+aps	. . . I am more content with myself	5	5	5	2	2	0.85
	Self-image						
+self	. . . I would like my body better	6	4	4	2	3	0.50
	Altruism						
+apo	. . . I am a role-model for others	10	0	4	4	1	0.01 *
	b) Barriers: adverse effects, negative consequences	Relevant	Not relevant	Relevant	Not relevant	No answer	p≤ 0.05
	Negative impact on self image						
-aps	. . . I would feel embarrassed if people saw me	1	9	7	0	1	0.01 *
-aps	. . . I feel uncomfortable or embarrassed using assistive devices	6	4	7	1	1	0.76
-aps	. . . have to give up things that I like doing	5	5	6	1	2	0.46
-aps	. . . I feel dependant on the use of assistive devices	5	5	8	0	1	0.07
-aps	. . . it gives me the image of being disabled	8	2	8	0	1	0.15
-aps	. . . I don't feel good using the assistive devices	3	7	7	1	1	0.04*
	Negative attitude of others						
-apo	. . . I am afraid to attract attention	3	7	7	0	2	0.04 *
-apo	. . . others may think I am arrogant	0	10	5	2	2	0.01 *
-apo	. . . it doesn't look nice	6	4	8	0	1	0.07
	Negative impact on others						
-oth	. . . it puts an extra burden on my significant others	3	7	7	1	1	0.04*
	Taking time from other things						
-oth	. . . it prevents me from spending time with my friends.	0	10	5	2	2	0.03 *
-self	. . . it would take too much of my time	1	9	6	1	2	0.01 *
-oth	. . . I would have less time for my family and friends	0	10	5	2	2	0.01 *
	Difficulties / effort						
-self	. . . there is too much I would have to learn to do it correctly	5	5	7	1	1	0.21

	Answers of RA participants (n=10)		Answers of occupational therapists (n=9)			Significance of difference in ratings between groups (X^2)
-self . . . I think I would be too tired to do my daily work	1	9	3	4	2	0.21
-self . . . I would be too exhausted at the end of the day to care for my joints	4	6	5	2	2	0.50
-self . . . the tasks are more time consuming /slower	5	5	6	1	2	0.46
-self . . . it is initially unusual and that can lead to tension	4	6	6	1	2	0.25
-self . . . I have to make more of an effort	4	6	7	1	1	0.10
-self . . . work becomes more difficult	5	5	7	1	1	0.21

Benefits and costs following Janis and Mann's theory of medical decision making:
+self = gains for self; +oth = gains for others; +aps = approval from self; +apo = approval from others.
-self = losses for self; -oth = losses for others; -aps = disapproval from self; -apo = disapproval from others.

B) Interviews with RA participants

The introductory question about RA participants' understanding and perceptions of JP identified many views, some of which were not in accordance with JP principles (Cordery and Rocchi 1998). They raised issues related to facilitators and barriers to using JP in their daily lives, as well as their positive and negative attitudes towards it. These are summarised in Table 3.

Table 3: RA participants' understanding and perceptions of Joint Protection (Themes are shown in bold type with associated clusters of meaning statements (n=10)

Understanding of JP
In accordance with JP principles
. . . maintain joint function by e.g. exercise, joint mobility, strengthening muscles; holding joints(s) physically in the right position (n=4)
. . . protect the joints by using assistive devices, e.g. jar opener, working splints * (n=4)
. . . a specific way of performing a task to help make activities easier, especially for the hands, e.g. work bilaterally (n=3)
. . . specific behaviour to preserve joints; can be achieved by different methods (n=2)
. . . keep pain to a minimum
. . . not work until fatigued / not over use, because fatigue leads to false positioning
. . . caring for the joints, even without assistive devices
Not in accordance with JP principles
. . . only during certain activities or when it's especially important (n=3)
. . . only when pain is present (n=1)
. . . not to use the joints, use as few as possible (n=1)
. . . I practise JP only when I don't have any pain (n=1)
Perceived facilitators and barriers for JP implementation in a daily context
Facilitators
. . . one must think ahead how to do it [activities], especially when pain is present. I am consistently aware of joints during certain tasks but during others not very much at all, when it is not necessary for that task
. . . use joints in daily life in a manner that protects joints, e.g. back behaviour (not bending forward when lifting a heavy load)
. . . discipline is important and one must make an active contribution, instead of letting oneself go
. . . repeating it constantly to get it automatic
Barriers
. . . sometimes it's easier, sometimes more difficult to do. It does not always work, because it depends on the situation
. . . I usually look after my joints, more on the right side than on the left . . . at the moment it's difficult because of pain
Positive or negative attitudes towards JP
Expressing disease acceptance
. . . at the beginning of the disease, it was less important. The longer the duration, the more important it is. One realises that it is necessary and helpful
. . . I perceive that JP helps, so then you do it
. . . if something is useful, it doesn't matter what other people think
Expressing negative attitude
. . . JP sounds like an obligation, like 'you have to'
. . . I often avoid JP and think it's not yet necessary

Perceived benefits of joint protection

RA participants explained, for most items, their relevance ratings of perceived benefits of JP in relation to their personal experiences (Table 2a). Four of the original benefit key themes (i.e. those identified during the questionnaire development phase) were confirmed and four new themes emerged. The key theme *'physical well-being'* was complemented by two new themes: '*reducing pain'* and *'improving function'*. The key theme *'personal control'* was complemented by the new theme *'active contribution'*. Finally the key theme *'disease acceptance'* emerged from *'self-acceptance', 'self-image' and 'altruism'* (Figure 1).

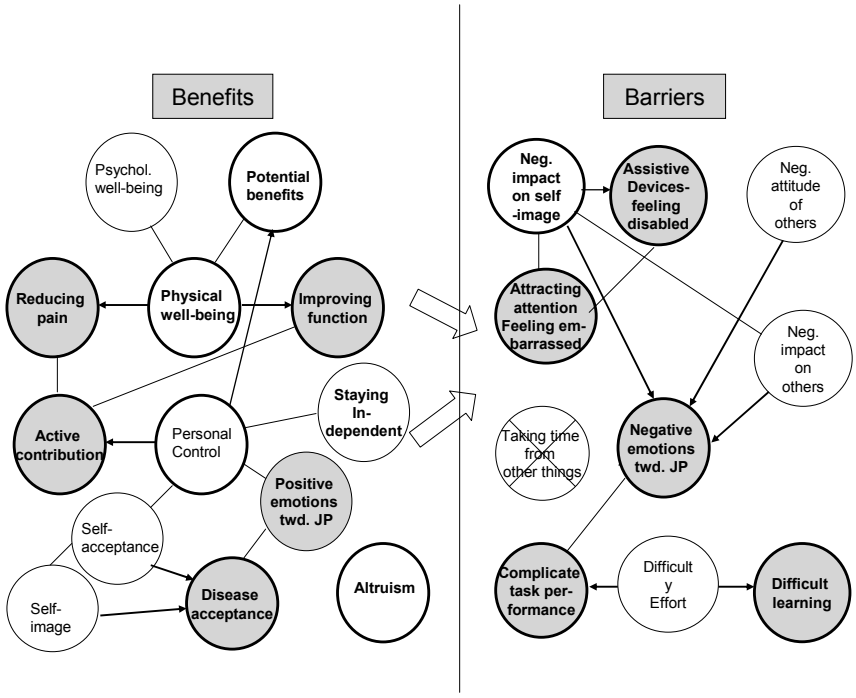

Figure 1: Key Themes of Decisional Balance for Joint Protection

White fields: original key themes (theoretical framework); Blue fields: complementary key themes from interviews; Bold circle: adjusted final key themes for JP Decisional Balance (constructivist framework). Small black lines mark most important relationships; Thick white arrows symbolise that increased perceived benefits, decreased relevance of perceived barriers.

Physical well-being: JP use was consistently associated with improving pain and function. These benefits were considered to also result in improved psychological wellbeing. JP was experienced as a helpful ergonomic technique to better cope with certain tasks. These positive experiences were further linked to Improvements in strength (Table 4; 1-3).

Potential benefits: The interviews revealed that the belief of *'preventing damage'* and *'saving later health costs'* varied in strength from hope to conviction amongst RA

participants. Nevertheless, the belief about potential long-term benefits may be an important motivation (Table 4; 4).

Personal control: JP use was consistently associated with making an *'active contribution'* to physical and psychological well-being. Two RA participants emphasised the importance of staying physically independent as a benefit of JP use (Table 4; 5-6).

Psychological well-being: Seven RA participants attributed improved psychological well-being to the use of JP, associating it with 'feeling better and more positive towards life' (2 patients), 'having less pain' (2 patients), 'less stress because of easier tasks performance (2 patients) and 'making an active contribution' (1 patient) (Table 4; 7). *'Positive effects on family and friends'* was the only item included representing gains for others (+oth), although no patients attributed such benefits from JP during interview.

Self-acceptance, self-image and altruism: The commitment to perform JP was associated with disease acceptance (Table 4: 8). *'Being more content with oneself'* was not commented on in the interviews. One person associated a positive self-image with a positive perception of her body and personal control and linked it with disease acceptance (Table 4.8). *'Being a role-model when performing JP'* (an approval of others item (+apo)) was rated relevant by all 10 RA participants, but no comments explained this rating.

B) Perceived barriers to joint protection

The RA participants generally revised and specified their questionnaire ratings during interview. They considered most barrier items as potential barriers for other people, but no longer for themselves, because as 'JP performers' they had now overcome them. In consequence, this explained why there was a significant disagreement between RA participants and OTs for most barrier items of the questionnaire (Table 2b).

One original barrier key theme was confirmed (*negative impact on self*), one was deleted (*'taking time from other things'*), and five new key themes emerged. The key themes *'attracting attention/feeling embarrassed'* and *'assistive devices/feeling disabled'* emerged from the themes *'negative impact on self image'* and *'negative attitudes of others'*. The key themes *'complicate task performance'* and *'difficult learning'* emerged as key themes from *'difficulties/effort'* (Figure 1).

Negative impact on self-image / negative attitudes of others: None of the RA participants reported negative experiences with others because of using JP. However, they discussed fears that using JP might attract attention and feeling embarrassed if this were to happen. It was these fears which had a negative impact on their self-image (Table 4:9).

The high ratings of the items '*feeling uncomfortable / embarrassed when using assistive devices,' 'giving the image of being disabled' and 'doesn't look nice'* were confirmed in the interviews. JP methods using alternative movement patterns can be done discreetly but using assistive devices makes disability obvious. Participants admitted to feeling dependent on the use of assistive devices but also perceived their benefits (Table 4; 9-10).

Difficulties/effort: Whilst RA participants perceived these items as potential barriers for others, the interview highlighted these were no longer problems for themselves. They acknowledged that initially JP may make task performance slower or more complicated and emphasised the need to perform JP as a habitual behaviour (Table 4; 11-12). Once JP was learnt, it was considered easy. Thus the item '*there is too much to learn to perform JP correctly'* seemed particularly relevant when starting to use JP.

Two RA participants emphasized that using JP allowed them to continue with their favourite activities, whilst three mentioned activities being given up, e.g. skiing, bowling. However, it was unclear if the latter had been done to protect their joints or just because they were struggling to do them because of their RA. Thus there was ambiguity about whether JP prevented or led to people giving up some activities.

Negative impact on others: For three RA participants, this perception seemed more related to having RA than to the performance of JP (Table 4; 13).

Taking time from other things: The RA participants' opinion was firmly that time costs were not relevant barriers for JP (Table 4; 14).

Table 4: Patients' experiences and perceptions of benefits and barriers (The key themes are presented separately for benefits and barriers and in descending order of relevance for patients and agreement with OTs

	Statements related to BENEFITS
Physical well-being	
1	JP Improving physical well-being associated with psychological well-being I can move better when I haven't provoked the pain. When I do things using JP it's better, then I feel less stressed (patient 5) One gets more aware of one's body and then can generally relax more [when doing activities] (patient 10)
2	Complementary key theme: JP as facilitator for reducing pain When I'm wearing working splints, I have less pain and I notice that it helps (patient 1) I feel more comfortable with my body . . . yes, because it makes things easier, does good. I can reduce pain by using assistive devices (patient 2)
3	Complementary key theme: JP as facilitator for improving function I can carry or lift much more, up to 3 kg when I'm using JP techniques (patient 4) In some activities I am limited but often need less strength with JP. Yes it's easier to perform routine physical tasks when using JP regularly, but when I have problems, my family helps (patient 5) I apply JP because it's useful and helps. Since I started to use JP regularly, it gets automatic and therefore easier and helps more (patient 10)
Potential benefit	
4	JP Potential benefits: prevent damage and save later costs for the health care system I just hope that JP helps prevent damage (patient 3) Because, in my case, I might avoid a joint replacement operation (patient 5)
Personal Control	
5	JP Improving personal control being associated with staying independent I am active myself and it is important for me not to have to always ask for help (patient 4) This as a very important reason, stay independent (patient 10)
6	Complementary key theme: JP as an active contribution When performing JP, I have the feeling of contributing something to help myself' (patient 2) With JP I can do something myself, with the idea that the disease doesn't get worse (patient 6)

7 Psychological well-being
I feel better during certain activities when applying JP (patient 1)
When I perform JP, I have more energy and feel less stressed because of less pain. Contributing actively to my health myself makes me feel better, more relaxed, more positive towards life (patient 2)

Self acceptance and self image

8 Complementary key theme: disease acceptance as facilitator for JP use
Commitment to perform JP regularly: . . . hmmm (patient thinks for a while) that can only happen after one accepts the disease . . . for me that is so after so many years (patient 4)
That has to do with acceptance of disease. Earlier I used JP when pain was present, these days I do it all the time (patient 5)

Statements related to BARRIERS

Negative impact on self-image / negative attitudes of others

9 **Complementary key theme: feeling embarrassed when asked**
I sometimes fear that people would ask me [why I was doing it] and I would have to explain my disease. But that has to do with acceptance of disease as well; the longer I have this chronic disease, the less I feel embarrassed (patient 5)
Personally it doesn't bother me when someone brings it up and starts asking about it, but for others it may be so. Yes, probably that is a reason for not use JP – one is not always in the mood for being confronted in public (patient 10)

10 **Complementary key theme: afraid to attract attention / feel disabled when using assistive devices as barrier for JP use**
I don't feel disabled, but maybe others do, when using assistive devices. But, often everybody asks "what's wrong with you", and then I have to explain (my situation) (patient 1)
Sometimes, yes, using assistive devices makes me feel disabled and I am afraid to attract attention when I use assistive devices; however, I do use a special knife in restaurants (patient 2)

Difficulties/effort

11 **Complementary key theme: to much/ too difficult to learn**
In the beginning it is difficult, you have to try hard or to think about it when it's not yet being performed as a matter of course. Tiredness doesn't play a role . . . eventually it got nearly automatic, especially when in pain (patient 4)
Yes. One must concentrate on it, it takes some time until it becomes automatic; at the beginning, I had to remember and concentrate. Then it's becomes the other way round, with experience you realise that without JP it is worse, - then you have understood the idea of JP (patient 10)

12 **Complementary key theme: Work becomes more difficult / slower**
This is because of this disease: I have to make more effort in everything (patient 2)
Yes perhaps, sometimes, it gets a bit slower, when one does it more carefully and pays attention to joints (patient 9)

13 **Negative impact on others**
They are sorry if they see me this way, then they understand how difficult my disease is. But I am a farmer and always at home, so it depends also on your job (patient 1)
Yes. But no, they shouldn't (suffer) and they don't have to feel sorry for me (patient 10)

14 **Taking time from other things:**
Time does not play a role for [using] JP (patient 1)
Time costs are irrelevant, at the beginning it may be important, but later it becomes unimportant . . . and automatic (patient.7)

Discussion

The mixed methods design applied in this study united the advantages of quantitative and qualitative approaches, with the latter clarifying the questionnaire findings. In the questionnaires, RA participants generally rated the benefit items as more relevant and the barriers as less relevant than the OTs. The interviews accessed the RA participants' everyday experiences. This allowed better understanding of the meaning underlying their ratings of potential benefits and barriers. Investigator triangulation was used for the interpretation of the interviews to increase the credibility and value of the findings.

RA participants generally reported an understanding of JP in accordance with JP principles (Cordery and Rocchi 1998), i.e. minimising pain, fatigue and making tasks easier. They all provided many experiences of applying JP methods in their daily life through planning, active management and developing automatic behaviours. Only two participants held JP concepts not in accordance with JP principles. One reported using joints as little as possible *'to protect them.*" However, this could make problems worse. The term 'joint protection' may be misleading and be contributing to such incorrect perceptions for some. The other participant stated they performed JP "*when not having pain.*" Again, this is not in accordance with the JP principles, as its purpose is to reduce pain.

Concordance among RA participants and OTs about the relevance of benefits related to '*physical wellbeing*, *'personal control'* and '*potential benefits'* reflects JP theory (Cordery 1965, Cordery and Rocchi 1998) and scientific evidence (Veehof et al. 2008, Taal et al. 1993, Hammond and Lincoln 1999, Agnew 1995). This suggests OTs effectively teach these benefits and RA participants perceive these from their experience. RA participants perceived the benefits related to '*psychological well-being'*, '*self-acceptance' "self image"* and '*altruism*' as more relevant than did the OTs. This suggests that, although OTs may not emphasize these benefits as much in JP education, they are clearly experienced by people with RA.

The substantial disagreements between people with RA and OTs in relation to the barrier items may be due to our sample. We selected "expert patients" so we could gain greater insight into attitudes towards and experiences of JP behaviour. However, the interviews clarified that these patients had perceived these barriers initially when learning JP, but in the course of time had overcome these. This confirmed they were now JP performers in the TTM stages of action or even maintenance. In contrast, OTs may have had patients in precontemplation or contemplation stages in mind, where such barriers are predominant (Prochaska 2008). People may not be ready to change if they are referred for JP education too early and not perceiving difficulties. A study of people with very early RA (6 months duration) with minimal hand problems identified no effects of JP education (Freeman et al. 2002). However, for people with early RA (approx 18 months) with hand pain and functional problems, JP education led to greater use of JP behaviours and longer-term significantly fewer hand deformities and maintained functional ability (Hammond and Freeman 2004).

Originally, the JP benefit and barrier items were conceptually allocated to seven benefit and five barriers key themes respectively. The interviews' analyses lead to a constructivist framework which turned out to be more complex. The key theme *physical well-being* was complemented by *reducing pain* and *improving function*. RA participants associated improved function directly with JP as an ergonomic technique, which also had an 'impact on strength'. Although JP theory does not suggest it improves strength, studies have identified JP increased grip strength in people more adherent with JP (Hammond and Freeman 2001, Niedermann et al. 2009a). A possible mechanism may be that reducing pain through JP enables people to do more with their hands and thus strength improves.

The key theme *personal control* was complemented by active *contribution as p*atients perceived themselves as being able to perform JP when necessary.

It has been shown in several studies that perceived benefits of JP and self-efficacy are both related to successful performance of JP methods (Hammond and Freeman 2001, Prochaska 2008, Niedermann et al. 2009b).

The key theme *'disease acceptance'* emerged from self-acceptance and self-image and was linked with positive emotions towards JP. None of these patients seemed to use JP as a disability badge, rather they were anxious about attracting attention and provoking questions from the social environment.

The negative impact attributed to the use of assistive devices by RA participants was surprising. Assistive devices are usually given to reduce functional problems and such patients usually seem satisfied (Veehof et al. 2008, Nordenskiold et al. 1998). The need for assistive devices may overstate a picture of disability that patients may not perceive or want to accept. Overall, it became clear that JP behaviour is not simply about doing everyday activities differently, but that the way this is done differently (for example, overly using assistive devices rather than alternative movement patterns) can impact on personal perceptions and self-image.

Many of the interviewed patients reported using JP methods only '*when it's necessary'* or *'in certain situations',* meaning they use JP when functional limitation or pain prompt a change in their working method. However, if (intermittent) pain or functional limitations are experienced and joints are already affected by the disease process, people with RA should be encouraged to use JP methods habitually or automatically, as it reduces the need to continually monitor performance and decide whether or not JP is necessary for each activity on each day. On the other hand, for those in full remission being 'back to normal', i.e. no longer using JP behaviour, is acceptable if joints are stable, i.e. deformities are not present. Our participants were being treated successfully with combination or biological drugs and thus may no longer perceive the need or have the motivation to consistently perform JP. However, a study of JP with people on anti-TNF medication has shown JP provides additional benefits (Masiero et al. 2007).

There are some limitations in this study. The interviews were performed only with patients with long disease duration who reported using JP. The perceived benefits and barriers may be different in patients with early RA or in those who have chosen not to use JP. Ten interviewees may have been an insufficient number to identify all aspects of

JP benefits and barriers. Additionally we recruited from a university hospital setting, which may mean patients received more JP education than in other settings. Benefits and barriers may be different amongst those who have received less input. Conducting the interviews after questionnaire analysis would have enabled more focused questioning and exploration of views. This was not possible with the simultaneous use of questionnaire and interview. Another limitation may be that the patients rated the questionnaire' items in the presence of the interviewer, whereas the OTs answered them independently. This different methodological approach may have impacted on the answers. Possibly patients were more likely to give "socially desirable" answers in a face-to-face interview, whereas OTs were less likely to do so in a postal questionnaire. Additionally, not all OTs rated all items and we do not know if this was because they did not want to or were unable to answer. The questionnaire developed had face validity and was designed to be exploratory in nature. We therefore did not investigate its construct validity or reliability prior to use. Statistical calculations of agreements between RA participants and OTs may therefore be questioned. Additionally multiple comparisons increase the risk of type I and II errors. However this analysis provided insights into substantial disagreements between people with RA and OTs more effectively than a descriptive approach alone. Additionally conducting interviews with the OTs would allow linking of their questionnaire ratings with interview responses, extending understanding of the OTs' JP perceptions.

Nevertheless, this study identified that people with RA and Rheumatology OTs generally share common ground in terms of beliefs about the benefits and barriers for JP. This is important as OTs beliefs towards JP may influence their efforts in motivating (or not) their patients to use JP. The 'expert' patients' views confirmed the importance of emphasising perceived benefits of JP. Their views also highlighted that, especially in the early stages of JP education, perceived barriers are critical for adopting or not adopting JP behaviour. Further research is needed to assess benefits and barriers in non-users and people with early RA. Developing a valid, reliable JP decisional balance scale, with a wider range of people with RA, may help to systematically and effectively address benefits and barriers in JP education.

Conclusions for clinical practice

This study suggests some recommendations that may enhance communication strategies in JP education:

1. Be aware that patients may have their own rationale for adopting JP methods or not
2. People who do not perform JP behaviour at all, or perform it irregularly, may need a motivational approach first before teaching JP practically.
3. Identify and discuss individually relevant benefits of and barriers to using JP
4. Use the key themes identified in this study to discuss potential benefits
    - Emphasize the benefits, especially physical well-being, reducing pain and improving function as well as personal control and active contribution

5. Use the key themes identified in this study to discuss potential barriers
   - Address the barriers using assistive devices, attracting attention/feeling embarrassed, and the effort required to learn JP methods
6. Consider disease acceptance as a potentially important facilitator (and limited acceptance as a barrier).
7. Start action-oriented JP education when patients are ready to implement changes
   - Place more effort in helping patients appreciate relevant benefits. Perceived benefits have to outweigh perceived barriers before starting action-oriented interventions
8. Teaching JP methods in individually meaningful occupations may support the experience of benefits and facilitate JP adherence

References

Agnew, P. (1995) Compliance in wearing wrist splints. J Occup Ther Res 15(3), 165-180.

Arnett FC, E.S., Bloch DA, McShane DJ, Fries JF, Cooper NS (1988) The American Rheumatism Association 1987 revised criteria for the classification of rheumatoid arthritis. Arthritis Rheum, 31, 315-24.

Basler, H., Herda, C., Keller, S. & Ridder, K. (1998) Selbstwirksamkeitserwartung, Entscheidungsbalance und rückenbewusstes Verhalten zur Prävention von Rückenschmerz. Z Med Psychol, 4:149-57.

Brühlmann, P., Stucki, G. & Michel, B. (1994) Evaluation of a German version of the physical dimension of the Health Assessment Questionnaire in patients with rheumatoid arthritis. J Rheumatol, 21, 1245-9.

Cordery, J. & Rocchi, M. (1998) Joint Protection and Fatigue Management. In Melvin J, Jensen G (Eds). Rheumatologic Rehabilitation: Assessment and Management. The American Occupational Therapy Association, Inc, Bethesda, pp. 279-322.

Cordery, J.C. (1965) Joint protection; a responsibility of the occupational therapist. Am J Occup Ther, 19(5), 285-94.

Creswell, J. (1995) Research design: Qualititative and quantitative approaches., Sage Thousand Oaks, CA.

Dezin, N. (ed.) (1978) The logic of naturalistic inquiry, McGraw-Hill, New York.

Freeman, K., Hammond, A. & Lincoln, N. (2002) Use of cognitive-behavioral arthritis education programmes in newly diagnosed rheumatoid arthritis. Clin Rehabil, 16, 828-36.

Hammond, A. & Freeman, K. (2001) One-year outcomes of a randomized controlled trial of an educational-behavioural joint protection programme for people with rheumatoid arthritis. Rheumatology (Oxdford), 40, 1044-51.

Hammond, A. & Freeman, K. (2004) The long-term outcomes from a randomized controlled trial of an educational-behavioural joint protection programme for people with rheumatoid arthritis. Clin Rehabil, 18, 520-8.

Hammond, A. & Lincoln, N. (1999) The effect of a joint protection education programme for people with rheumatoid arthritis. Clin Rehabil, 13, 392-400.

Hochberg, M., Chang, R., Dwosh, I., Lindsey, S., Pincus, T. & Wolfe, F. (1992) The American College of Rheumatology 1991 revised criteria for the classification of global functional status in rheumatoid arthritis. Arthritis Rheum, 35, 498-502.

Iversen, M.D., Eaton, H.M. & Daltroy, L.H. (2004) How rheumatologists and patients with rheumatoid arthritis discuss exercise and the influence of discussions on exercise prescriptions. Arthritis Rheum, 51(1), 63-72.

Janis, I. & Mann, I. (1968) A conflict-theory approach to attitude change and decision making. In Psychological foundations of attitudes (A., G., Brook, T. and Ostrom, T. eds.) Academic Press, New York, pp. 327-360.

Janis, I.L. & Mann, I. (1977) Decision making: A psychological analysis of confilict, choice and committment., Free Press, New York.

Jones, J. & Hunter, D. (1995) Consensus methods for medical and health services research. Bmj, 311(7001), 376-80.

Marcus, B.H., Rakowski, W. & Rossi, J.S. (1992) Assessing motivational readiness and decision making for exercise. Health Psychol, 11(4), 257-61.

Masiero, S., Boniolo, A., Wassermann, L., Machiedo, H., Volante, D. & Punzi, L. (2007) Effects of an educational-behavioral joint protection program on people with moderate to severe rheumatoid arthritis: a randomized controlled trial. Clin Rheumatol, 26(12), 2043-50.

Merton, R. & Kendell, P. (1979) Das fokussierte Interview. In Qualitative Sozialforschung(Hopf, C. and Weingarten, E. eds.) Klett, Stuttgart.

Molenaar, N. (ed.) (1982) Response-effects of 'formal' characteristics of questions, Academic New York.

Newman, S., Steed, L. & Mulligan, K. (2004) Self-management interventions for chronic illness. Lancet, 364(9444), 1523-37.

Niedermann, K., Büchi, S., Ciurea, A., Kubli, R., Steurer-Stey, C., Villiger, P. & de Bie, R. (2009b) 6 and 12 months' effects of individual joint protection education in people with rheumatoid arthritis: A randomized controlled trial. In review

Niedermann, K., de Bie, R., Kubli, R., Ciurea, A., Steurer-Stey, C., Villiger, P. & Büchi, S. (2010) Effectiveness of individual resource-oriented joint protection education in people with rheumatoid arthritis. A randomized controlled trial. In press (Patient Education and Couselling)

Nigg, C., Rossi, J., Norman, G. & Benisovich, S. (1998) Structure of decisional balance for exercise adoption. Ann Behav Med, 20(S20).

Nordenskiold, U., Grimby, G. & Dahlin-Ivanoff, S. (1998) Questionnaire to evaluate the effects of assistive devices and altered working methods in women with rheumatoid arthritis. Clin Rheumatol, 17, 6-16.

Prevoo, M., van 't Hof, M., Kuper, H., van Leeuwen, M., van de Putte, L. & van Riel, P. (1995) Modified disease activity scores that include twenty-eight-joint counts. Development and validation in a prospective longitudinal study of patients with rheumatoid arthritis. Arthritis Rheum, 38, 44-48.

Price, P.E. (2008) Education, psychology and 'compliance'. Diabetes Metab Res Rev, 24 Suppl 1, S101-5.

Prochaska, J.O. (2008) Decision making in the transtheoretical model of behavior change. Med Decis Making, 28(6), 845-9.

Prochaska, J.O., DiClemente, C.C. & Norcross, J.C. (1992) In search of how people change. Applications to addictive behaviors. Am Psychol, 47(9), 1102-14.

Prochaska, J.O., Velicer, W.F., Rossi, J.S., Goldstein, M.G., Marcus, B.H., Rakowski, W., Fiore, C., Harlow, L.L., Redding, C.A., Rosenbloom, D. & et al. (1994) Stages of change and decisional balance for 12 problem behaviors. Health Psychol, 13(1), 39-46.

Smith, J., Flowers, P. & Osborn, M. (1997) Interpretative phenomenological analysis and the psychology of health and illness. In Material discourses of health and illnessRoutledge, London, pp. 68-91.

Smith, J., Jarman, M. & Osborn, M. (1999) Doing interpretative phenomenological analysis. In Qualitative health psychology(Murray, M. and Chamberlain, K. eds.) Sage, London.

Taal, E., Rasker, J.J., Seydel, E.R. & Wiegman, O. (1993) Health status, adherence with health recommendations, self-efficacy and social support in patients with rheumatoid arthritis. Patient Educ Couns, 20(2-3), 63-76.

van Gestel, A.M., Haagsma, C.J. & van Riel, P.L. (1998) Validation of rheumatoid arthritis improvement criteria that include simplified joint counts. Arthritis Rheum, 41(10), 1845-50.

Veehof, M.M., Taal, E., Willems, M.J. & van de Laar, M.A. (2008) Determinants of the use of wrist working splints in rheumatoid arthritis. Arthritis Rheum, 59(4), 531-6.

Chapter 5

Development and validation of a joint protection self-efficacy scale (JP-SES) using Rasch analysis

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Abstract

Introduction: Self-efficacy is one of the most powerful determinants of behaviour change. To increase effectiveness of joint protection (JP) education, it may be important to address perceptions of JP self-efficacy directly. The aim of this study was to develop a scale to measure JP self-efficacy (JP-SES) in people with RA

Methods: Instrument development included item generation, construct validity and reliability testing. Rasch analysis was applied to determine construct validity and the revised JP-SES was tested again to confirm validity and establish test-retest reliability and internal consistency.

Results: 46 items were generated by literature review, occupational therapists and people with RA. After semi-structured interviews and field-testing with RA participants, a 26-item questionnaire draft was constructed and tested. Rasch analysis to determine construct validity reduced the JP-SES to 13 items with good overall fit values. Rasch analysis of confirmatory validity resulted in a final 10-item version of the JP-SES. Test-retest results supported the validity of the scale, with high internal consistency (α=0.92) and good test-retest reliability (r_s= 0.79; p<0.001).

Conclusions: The JP-SES is a valid and reliable scale to assess perceived ability of people with RA to apply JP methods. The JP-SES could help stimulate the use of efficacy-enhancing methods in JP education.

Key words: occupational therapy, rehabilitation, validation, joint protection, self-efficacy, Rasch analysis, rheumatoid arthritis,

Introduction

Self-efficacy is one of the most powerful determinants of behaviour. According to Bandura (1) the confidence of a person to successfully execute a future specific behaviour or task, i.e. (self)-efficacy expectation, and the person's belief that the desired behaviour has a positive effect, i.e. outcome expectation, determine the initiation of a process to perform a behaviour, continue with it and persevere when difficulties arise. Self-efficacy refers to perceived ability in specific domains of activities, i.e. it is a specific state, not a general trait, although a variety and range of positive mastery experiences may lead to a general sense of self-efficacy. For example, a person with rheumatoid arthritis (RA) could potentially have high self-efficacy to follow a drug prescription correctly, but low self-efficacy for using joint protection (JP) methods correctly, i.e. in accordance with JP principles. Self-efficacy is a *belief* that one is able to perform a specific behaviour or task, rather than indicating that one actually does perform it. However the perceived ability to perform a given behaviour is strongly related to one's actual performance of that behaviour (1, 2).

In people with RA, higher self-efficacy has been shown to be associated with better ability to cope with their disease, i.e. manage pain (3) and daily living with RA (4), as well as with better current (5) and future (2 and 5 year) health status (6, 7). Applying self-efficacy approaches within education programmes increased use of exercise, relaxation, cognitive symptom and fatigue management and joint protection (4, 8-10) Self-efficacy is thus a strong mediator of behaviour change.

Hands are the commonest joints affected and hand involvement is one of the major problems from the RA patients' perspective (11). In consequence, occupational therapists (OTs) providing joint protection (JP) education to people with RA mainly focus on the hand and wrist joints (12). JP education aims to reduce pain and maintain functional ability. It includes applying ergonomics, altering working methods, balancing activity and rest and using assistive devices. In line with progress in drug therapy for RA, JP education has evolved from increasing knowledge about how to preserve joint structures and joint function to a self-management approach to cope with pain, reduce functional limitations and thus improve daily task and role performance. Studies consistently demonstrate that JP improves function and pain in the short- and long-term, given that psycho-educational methods are applied (13-15). However this approach is not commonly adopted. In Switzerland JP education typically consists of oral and written information about RA and JP principles (16); demonstrations and supervised practice of hand JP methods, mostly in a kitchen activity; and demonstration of appropriate assistive devices. This is provided in a one-to-one setting for between 1-4 hours over 1-9 sessions, dependent on the therapist's evaluation of patient need and staffing levels.

In a psycho-educational JP approach, practice under supervision and at home, goal setting and feedback, observing and exchange with peers in groups, discussions and verbal persuasion are important strategies. These learning and practice situations to acquire JP behaviours are also the four sources for acquiring self-efficacy: 1) direct personal mastery experience (skills performance with increasing difficulty and complex-

ity); 2) vicarious experience (role modelling), 3) verbal persuasion (counselling, suggestions, reinforcement and 4) emotional arousal (re-interpretation of physiological signals). Direct experience is far more effective than indirect experience (1). However, self-efficacy should also be addressed directly, by evaluating and supporting the patients' belief in their ability to acquire, perform and adhere to JP behaviour.

The Arthritis Self-Efficacy Scale (ASES) (2) is the most recognized instrument for assessing self-efficacy in people with RA. The ASES pain and other symptoms subscales have also been used in JP studies (13, 15). As self-efficacy is domain-specific, using a JP self-efficacy instrument may be more specific than the ASES in this context. Domain-specific self-efficacy scales, such as those for back pain (17) and physical activity (18), can contribute to determine which situations are important for the perceived ability to perform the target behaviour and for understanding how to tailor interventions to meet individual needs. A JP specific self-efficacy scale could offer similar benefits. Consequently, the aim of this study was to develop and evaluate the psychometric properties of a JP self-efficacy scale (JP-SES) for use in research and clinical practice.

Materials and Methods

Design

The development of the JP-SES consisted of six steps (outlined in Table 1).

Table 1: Overview of steps in the development of the Joint Protection Self-Efficacy Scale

Step (n = number of people with RA included)	**Procedures**
1. Item generation	33 items derived from related self-efficacy scales 9 additional items generated by occupational therapists 4 additional items suggested by patients 46 items
2. Construction of draft questionnaire	12 items removed (judged *not relevant* by patients) 3 duplicate items removed Draft version 1: 31 items
3. Preliminary testing / cognitive debriefing (n=9)	Minor changes / refinements in item formulation 5 items removed (perceived too general or redundant) Adding 2 additional response options Draft version 2: 26 items, 5 response categories (0-4)
4. Construct validity study (n=101)	5 items removed (not applicable for > 30% of patients) Application of Rasch analysis for construct validity Collapsing two response categories as disordered 8 items removed due to misfit Draft version 3: 13 items, 4 response categories (0-3)
5. Confirmatory construct validity study (n=125)	Rasch Analysis 3 items removed: 2 due to misfit; 1 due to DIF* Final version: 10 items, 4 response categories (0-3)
6. Test-retest reliability study (n=110)	Rasch analysis calculating summary fit statistics Calculating internal consistency and test-retest correlation

* DIF= Differential Item Functioning

Participants

Patients: Different groups of people with RA attending the outpatient facility of a hospital's rheumatology department participated in the scale development. The Local Research Ethics Committee approved the study protocol and patients provided informed consent prior to participation.

Occupational therapists (OTs): Therapists experienced in JP education, working in four different rheumatology outpatient facilities, participated in the item generation process.

Steps of scale development

Step 1: Item generation

The first set of items was composed by a group of five OTs, led by the principal investigator (KN). Items were selected and adapted through consensus from the contents of self-efficacy scales for back pain prevention behaviours (17) and physical activity (18), as items included in these scales are potentially also relevant to JP behaviour and thus JP self-efficacy. Items from these scales that were not adaptable for hand JP specifically were therefore omitted, primarily to ensure that the JP-SES content would be applicable to the majority of people with RA. Other items were generated from the OT's clinical experience. Semi-structured interviews were conducted with a convenience sample of 10 participants with RA who had previously attended "typical" individual JP education (see Introduction).

Firstly, they were asked to judge the relevance of each item (yes/no), and then to consider if, for these tasks or situations, JP would be difficult. Secondly, patients were asked to suggest additional items.

Step 2: Construction of a draft questionnaire

Version 1 of the JP-SES draft was developed containing all items from the list judged relevant by at least half of the RA participants, as well as the newly suggested items. A short explanation of self-efficacy and JP methods was included to enable participants' understanding of the underlying concepts of JP. The root statement "I *am confident that I can care for my joints when I am . . .*" *(17)* was combined with each of the selected items. These items were conceptually allocated to five areas: 'physical activities' (11 items), 'affect' (8 items), 'time constraints' (3 items), 'social activities' (7 items) and 'pain' (2 items). A 5-point response scale (0=not at all confident; 4=very confident), was applied as in the back pain prevention self-efficacy scale (17).

Step 3: Preliminary testing

The principal investigator asked participants with RA, currently attending JP education, to complete the version 1 of the JP-SES draft. They were then each interviewed regarding adequacy and comprehensiveness of the selected items (cognitive debriefing).

Step 4: Construct validity study
Version 2 of the JP-SES draft was distributed by treating rheumatologists to a consecutive sample of German-speaking RA patients. A sample size of 150 (n range 108-243) and of 100 (n range, 64-144) was identified as appropriate based on providing a 99% and 95% respectively confidence of item calibration of +/-0.5 logits (19).

Most or all of these participants would have received "typical" individual JP education as referral to OT was part of usual care at the participating hospital. They were asked to return the completed questionnaire within a week. Non-responders received a reminder after approximately two weeks. Additionally, disease activity (using the DAS28) (20), pain level (on a 0-10 visual analogue scale) and functional disability (Health Assessment Questionnaire, HAQ) (21) were assessed.

Steps 5 and 6: Confirmatory construct validity study and test-retest reliability
Version 3 of the JP-SES draft was sent to German-speaking people with RA taking part in a clinical quality management project at the participating hospital. Again most or all would have received "typical" JP education. Disease-specific data, pain and HAQ disability were also assessed. The patient information letter was non-specific about completing the questionnaire a second time (i.e. to test stability of questions) so as to reduce the likelihood of patients memorizing or recording answers. All responding patients were re-sent the questionnaire for reliability testing approximately three weeks later.

Statistics

The psychometric properties of the JP-SES drafts were tested with Rasch analysis (22-24), in order to examine how well observed data fit the Rasch model's expectations. For this, various error estimates and fit statistics are calculated and response category ordering and differential item functioning (DIF) (i.e. do items work the same way irrespective of group, e.g. gender) are examined. Additionally, if data fit the model, linear transformation of ordinal raw data is obtained, allowing for valid parametric statistics.

For construct validation (step 4) and confirmatory analysis (step 5), data from the Version 2 of the JP-SES draft were fitted to the Rasch Partial Credit Model ($\ln(p_{nij}/1\text{-}p_{nij\text{-}1})=\theta_n-\delta_{ij}$). Overall summary fit statistics were calculated to test the model fit of the JP-SES data: item-person interaction statistics (transformed to standardized normal distribution with expected overall item and person fit means of 0 and standard deviations of 1; and item-trait interaction chi square statistic, which, if significant ($p<0.05$), would indicate violation of the rule of invariance across trait. In addition, individual item fit was calculated, with significance level of 0.05. Before removing misfitting items, response category ordering was checked. If disordered, collapsing of adjacent categories may improve overall fit to the model.

DIF assessed bias for gender, younger/older age, short/long disease duration, low/high pain level and low/high disease activity. Bias may manifest as uniform DIF (consistent ability difference between groups) and/or non-uniform DIF (inconsistent ability difference, referred to as class intervals, between groups). Items displaying mul-

tiple uniform and non-uniform DIF at the 0.05 significance level (i.e. <0.05) were deleted.

On the final solution with all fitting items free of DIF, unidimensionality was formally tested using Principal Component Analysis PCA by examining principal component loadings of residuals (25, 26). Positively loading items were equated with negatively loading items and a series of independent t-tests was then performed to compare person location estimates by using differing item subsets. Less than 5% of these tests should be significant to confirm unidimensionality. Internal consistency (reliability) was assessed by the person separation index (PSI), which is equivalent to Cronbach's alpha. A value of at least 0.70 would be adequate for demonstrating internal consistency at group level, or 0.85 at individual level (27).

The Spearman rank correlation coefficient was calculated for test-retest correlation (using person locations) and Pearson correlation coefficients to explore associations between JP-self efficacy and disease status. Rasch analysis was performed using RUMM2020 software package (RUMM Laboratory, Dungraig, Western Australia). Statistical testing and reliability calculations were performed using SPSS software, version 12.0 (SPSS, Chicago, IL).

Results

Step 1: Item generation

A set of 46 items was identified: 33 from the two self-efficacy questionnaires (17, 18), nine by therapists and four by people with RA. Interviews were conducted with eight female and two male participants RA (mean age 60.40 years (SD 12.79), with mean disease duration of 17.40 years (SD 9.97). Interviews lasted between 15 to 30 minutes.

Step 2: Construction of a draft questionnaire

The version 1 of the JP-SES draft contained 31 items, after removing 12 items judged as not relevant by the majority of RA participants during the interviews and three items due to duplication.

Step 3: Preliminary testing

Cognitive debriefing of the version 1 of the JP-SES draft was performed with nine other RA patients. It took 5-10 minutes for them to complete the 31-item JP-SES draft. Five items, all from the area 'social activities' were perceived as either too general or redundant and removed: '*at a party', 'on vacation', 'travelling", 'having guests', 'eating out'*. No new items were suggested. After this process two response categories of *'not possible because of RA'* and *'not applicable for me'* were added to reduce missing data. This version 2 of the JP-SES draft, consisting of 26 items, was used in the next step.

Step 4: Construct validity

A total of 114 people with RA agreed to participate and 101 (89%) questionnaires were returned. Participants' disease-specific data in both validation studies (steps 4 and 5)

are presented in Table 2. The additional response category 'not applicable' was reported by 30% or more of respondents for several items: '*not supported by colleagues'* (59.4%; n=60); '*not supported by employer'* (53.5%; n=54); '*gardening'* (44.6%; n=45); '*assistive device gets dirty whilst using'* (30.7%; n=31); and '*driving'* (29.7%, n=30). These were therefore removed.

Rasch analysis was performed on the remaining 21 items to identify misfit to model expectations and DIF. The response options of several items were found to be disordered. Two adjacent categories were collapsed and then eight items removed due to misfit ('*in pain', 'not in pain', 'lifting heavy objects', 'carrying heavy objects', 'eating', 'cleaning', 'stressed', and 'feeling tense')* in a stepwise procedure. This resulted in a 13-item JP-SES (draft version 3) with four response categories (0=not at all confident to 3=very confident).

Table 2: Demographic and clinical characteristics of study participants

	Construct Validity Study Step 4 (n = 101)	**Confirmatory Study Step 5 (n = 126)**
Female (%)	78 (78%)	93 (74%)
Age (years)	58.6 (13.7)	59.0 (12.9)
Disease duration (years)	12.8 (8.3)	13.0 (9.3)
Rheumatoid nodules (%)	25 (25%)	28 (22%)
Rheumatoid factor (%)	85 (85%)	97 (77%)
Anti-CCP antibodies, where available (%)	NA	43/56 (77%)
ANA, where available (%)	48/84 (40%)	57/109 (52%)
Erosions (%)	73 (73%)	96 (76%)
DMARDs (no. of patients and %)	80 (79%)	122 (97%)
Steroids (no. of patients)	36 (36%)	48 (38%)
NSAIDs (no. of patients)	19 (19%)	28 (22%)
DAS28, mean (SD)	3.3 (1.5)	3.2 (1.2)
Hand pain (VAS 0-10)	3.1 (2.6)	2.9 (2.4)
HAQ score (0-3)	1.0 (0.6)	0.9 (0.7)

Values are the mean (SD), unless stated otherwise; NA = not available.
ANA = anti-nuclear antibodies, Anti-CPP = anti-cyclic citrullinated peptide, DMARDs = disease-modifying anti-rheumatic drugs; NSAIDs = non-steroidal anti-inflammatory drugs; DAS28 = Disease Activity Score in 28 joints; ESR = erythrocyte sedimentation rate; HAQ = Health Assessment Questionnaire

Step 5: Confirmatory construct validity

The version 3 of the JP-SES draft was sent to 175 German-speaking RA patients of whom 126 (72%) responded (see Table 2). Rasch analysis was performed on complete data from 116 participants with RA (87 women and 29 men).

Rasch modeling identified two further items with misfit ('*feeling depressed' and 'using an assistive device'*) and one item with DIF for gender and pain ('*feeling anxious'*). After removing them, the analysis resulted in the final 10-item JP-SES with good overall fit: item fit mean of 0.0 (SD 0.70), person fit mean of -0.10 (SD 2.33) and total item chi square of 24.32 (df = 20; p=0.23). Six of the final items were identical with ones derived

from the two self-efficacy scales for exercise (4 items) and back pain prevention (2 items).

Individual item fit statistics ranged from p values of 0.92 to 0.08, i.e. items did not significantly differ from the model. Individual item difficulty level ranged from -0.80 (lowest requirement of self-efficacy) to 0.99 (highest requirement of self-efficacy) (Table 3).

Table 3: Fit of the final 10 items of the Joint Protection –Self Efficacy Scale (JP-SES) (in descending order of p-values)

I am confident that I can care for my joints when I . . .	Mean Location = item difficulty	Fit Residual	X^2 value	P value
Items representing 'physical activities'				
lift a light object	-0.27	-0.24	0.55	0.76
carry a light object	-0.49	-0.43	0.96	0.62
cook *	-0.80	1.12	2.69	0.26
shop	-0.71	3.18	4.63	0.10
write	-0.76	0.33	5.05	0.08
Items representing 'affect'				
am in a bad mood §	0.99	0.95	0.16	0.92
am being watched	0.26	-1.38	1.73	0.42
do not feel like it	0.75	-1.03	2.43	0.30
am very busy	0.18	-0.26	2.64	0.27
have no time	0.83	-1.46	3.49	0.17

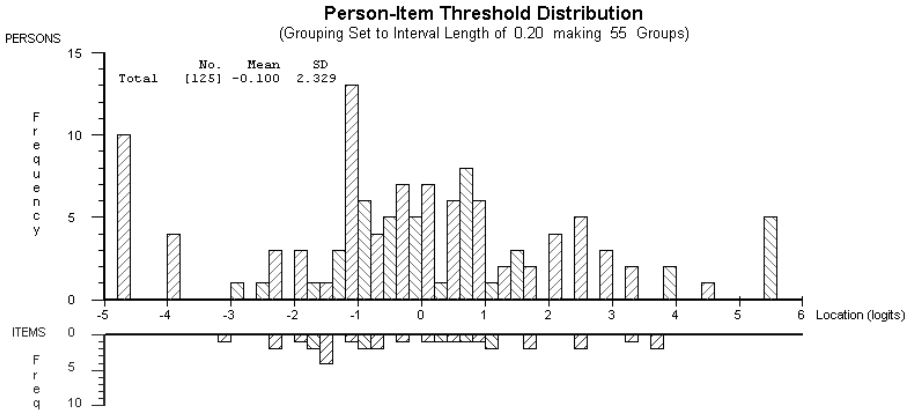
§ Most difficult item = requiring most self-efficacy, * easiest item = requiring least self-efficacy (mean location)

The person-item threshold distribution (Figure 1) shows that the items' difficulty targeted the persons' ability well. For some people with very high (or very low) self-perceived ability, there were no items in the scale to capture this.

Internal consistency: Person separation index (PSI), (which corresponds to Cronbach's alpha, i.e. reliability) was high (0.95), allowing use of the scale at the individual level. This step confirmed construct validity of the final version of the JP-SES (Appendix 1). Principal Component Analysis PCA of the residuals identified two subsets of items consisting of the highest positive and negative loading items. The positive subset (PC loadings >0.3) comprised four items related to 'affect' (*in a bad mood, not feel like, no time, busy*) and the negative subset (PC loadings <-0.3) comprised five items related to physical activities (*cook, shop, write, lift light weight, carry light weight*). The equating/independent t-tests of the person estimates for the positive loading and negative loading subsets showed 4.08% of the tests were significant, which supported the assumption of unidimensionality of JP self-efficacy across the areas of 'affect' and 'physical activities"

Correlations: Pearson's correlations of the total JP-SES score (from the confirmatory study) with disease related factors were low although significant: 0.19 (p=0.03) for pain; 0.22 (p=0.02) for DAS28; and 0.27 (p=0.008) for the HAQ disability index.

Figure 1: Person / Item-Threshold Targeting Graph of the JP-SES (persons n=125; items n=10) Locations of persons (= person abilities) and of each item threshold on the interval scale, representing the measure of JP self-efficacy.



Easiest item threshold is from 'not at all confident' to 'a little confident' for the item 'writing' with mean logit of –2.75 (on the left). Most difficult item thresholds are from 'quite confident' to 'very confident' for the tasks 'lacking time' and 'in a bad mood' with mean logits of 3.47 and 3.49 respectively (on the right).

Step 6: Test-retest – reliability

The test re-test sample consisted of all responding participants in step 5 (n=126). Of these, 110 (79 women: 31 men; 87%) returned the second questionnaire with complete data. Rasch summary fit statistics were: item fit mean 0.0 (SD 0.61), person fit mean 0.18 (SD 2.24) and total item chi-square 21.56 (df =20; p=0.37). Individual item fit statistics ranged from p values of 0.92 to 0.07. Individual item difficulty level ranged from -0.92 to 0.90 (lowest to highest requirement of self-efficacy). PSI of the re-test scale data was also 0.95, once again high enough for use in individuals and groups.

Mean total JP-SES scores of the confirmatory construct validity study and retest study were 14.94 (SD 8.08) (n=126) and 16.22 (SD 8.52) respectively (n=110). Cronbach's alpha for internal consistency of the items in both of the two samples was $\alpha = 0.92$. The test-retest reliability Spearman rank correlation was 0.78 ($p<0.001$).

Discussion

The JP-SES was developed to assess how people with RA rate their perceived ability to perform hand JP methods, as these are the commonest methods used by people with RA and taught by OTs. Overall, it demonstrated good validity and reliability and can be used for research purposes to evaluate effectiveness of JP education or changes in JP-SE over time.

Item reduction of the JP-SES items initially generated was necessary to determine the final set valid for assessing JP self-efficacy. Items removed were all within the areas 'physical activities' and "affect'. Items related to 'affect' generally appeared more difficult, almost acting as 'barriers' and thus requiring more self-efficacy than activity items

(Table 3). Some difficult 'physical activity' items were deleted due to misfit or serious DIF (e.g. *'lifting heavy objects', 'carrying heavy objects', 'cleaning')* and items representing (negative) affect in a more general way (e.g. *'stressed'*, *'feeling tense'*). These situations may practically make performance of JP methods more difficult, rather than affect perceived ability of performance per se. All items, within the areas 'time constraints' and 'social activities', as well as the two pain items, showed misfit and DIF and were therefore discarded. Although pain has been found to strongly determine the performance of JP methods (28, 29), being *'in pain* or *'not in pain"* was not related to perceived ability to apply JP methods. Six of the ten final items were identical with the self-efficacy scales for exercise and back pain prevention. Although SE is domain-specific, it may be covered by identical or similar items across related domains.

The set of the final, unidimensional items, i.e. fitting the Rasch model, allowed for an interval scale transformation of the (ordinal) raw scores. This is especially important in an evaluative instrument where correct change scores have to be calculated (30). Test-retest reliability was good. For estimating response stability over time, stability of the disease condition has to be assumed. RA is a disease with unpredictable daily changes, although the disease variables pain, DAS28 and HAQ were similar at both time points. Also correlations between the disease variables with the psychological construct of JP self-efficacy were significant but low, indicating these have less effect on self-perceived ability of JP performance.

Rasch analysis, considered state-of-the-art in the development of new scales, was applied ensuring unidimensionality of the JP-SES as a fundamental requirement for construct validity (20). A potential limitation of the study thus was its relatively small sample size. We originally planned to obtain a sample size of 100 -150 as this would provide between 95-99% confidence of item calibration and we achieved this. For tests that are not well targeted, larger sample sizes are required for adequate item location precision (19). The well-targeted JP-SES reduced its sample sized requirements, which conversely, could have challenged the validity of the JP-SES. No floor or ceiling effects were present (31). Whilst further development work on the scale may improve the JP-SES' coverage by adding very easy and very difficult items, it should be considered that items that everybody achieves (i.e. very easy ones) or items that everyone misses (i.e. too difficult ones) may not add much information to a scale. We used a 5-point response scale initially. Many self-efficacy scales use 0-10 numeric rating scales (2, 18, 32) and some use Likert-type scales of five response options (17, 33). Generally, the extension of response categories to improve gain of information (sensitivity) and reliability is advocated (34). However, there is conflict between improving precision and reliability by raising the number of response categories and people's limited channel capacity, i.e. their (in)ability to discriminate between narrow scales (35, 36). Reducing the number of response categories can, in some circumstances, result in instruments with lower cognitive burden without loss of sensitivity or reliability (37, 38). Rasch analysis addresses response category ordering and participants' inability to discriminate between response categories may result in disordered response options that are breaking the rule of scale additivity. This tension - between precision and ability to discriminate in the JP-SES

scales - was demonstrated in our analysis, where several items had disordered categories. The 5-response categories in these items were not distinguishable for all patients and therefore provided no additional useful information. Interestingly, reducing to a 4-point response scale was the best solution and provided a better item fit than performing the same Rasch modelling procedure with a trichotomous or dichotomous scale.

The focus of the study lied on the distinct steps of a development process and use of Rasch analysis, to determine validity. A limitation of the study is that no other psychological constructs were used in this validation process. Future research to support the construct validity of the JP-SES should investigate associations with other psychological constructs or self-efficacy subscales, e.g. the Rheumatoid Arthritis Self-Efficacy scale (39).

The JP-SES was primarily developed and validated for use in research in group studies. If the aim is change scores are calculated parametric statistics are used, the (ordinal) raw scores have to be transformed into interval scores. Theoretically, scales with raw scores developed using Rasch analysis can be used clinically on an individual level if a score-to-measure conversion table is developed, translating ordinal (raw) scores to interval data, which would give a person location, i.e. information about the patient's ability (in this context in terms of JP self-efficacy). A valid conversion table must be produced with a large patient sample (40) and this would only then be applicable to people of similar characteristics, e.g. diagnosis and age range. Such conversion tables may be of limited use for individual clinical assessment, as well as making scoring more complex. However, because the person separation index reliability was high, the JP-SES can be used on an individual level and raw scores used to create scale totals.

Clinical use of the JP-SES in individuals may be more appropriate for screening patients' tasks and perceptions of JP use in the assessment prior to JP education. To improve patients' self-efficacy, it may also be important to identify outcome expectations (i.e. beliefs in JP effectiveness), which may also be preconditions for improving perceived ability to cope (2). The JP-SES could help stimulate consciously applying efficacy enhancing methods (e.g. individual goal setting, specific instructions and practice, contracting, modeling, reinterpretation of physiological signals) in JP education (4).

Self-efficacy is not an easy concept to understand for patients. Some participants would have preferred the statement *'I am confident to care for my joints when I am . . . '* to be changed into *'I care for my joints when I am . . . '*. However, this would be much more than a semantic change. The difference between the statement about performing JP during an activity and the 'hypothetical' statement of perceived ability to perform JP in certain situations should be emphasized in instructions.

The modern concept of JP education as a self-management approach requires psycho-educational teaching methods. Such methods, among them self-efficacy enhancing strategies should be more widely adopted. In this context, a more appropriate term, such as 'ergonomic education' would better reflect the modern JP concept.

The value of the JP-SES is to provide information about the patient's perceived ability to perform JP and to help plan treatment, e.g. by goal setting and conscious use of self-efficacy enhancing methods. Further research is needed to determine the scale

responsiveness and its usefulness as an evaluative instrument, as well as to understand how JP self-efficacy and JP performance are related.

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Competing interests
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Appendix

German Version of the JP-SES and *Corresponding English Translation*
Fragebogen zur Zuversicht für Gelenkschutz / *Joint Protection Self-Efficacy Scale*

Dieser Fragebogen erfasst Ihre Zuversicht, d.h. Ihr Vertrauen in Ihre Fähigkeit, bei verschiedenen Tätigkeiten und in verschiedenen Situationen auf Ihre Hand- und Fingergelenke zu achten und Gelenkschutz-Methoden anzuwenden. Gelenkschutz heisst:

- die Hand- und Fingergelenke in möglichst natürlichen und gelenkschonenden Stellungen belasten
- kraftraubendes Heben und Tragen vermeiden
- bei Tätigkeiten möglichst beide Hände zu gebrauchen
- für bestimmte Tätigkeiten ein Hilfsmittel benützen

Bitte kreuzen Sie für jede Situation das entsprechende Feld an, auch wenn etwas nicht vorkommt.

- This questionnaire assesses your confidence in your ability to care for your wrist and finger joints in different activities and situations using joint protection methods. Joint protection means
- using your wrist and finger joints in their most stable natural and joint-friendly position
- avoiding lifting and carrying weights
- using both hands for tasks whenever possible
- using an assistive device for certain tasks

Please tick the appropriate answer or tick if not applicable.

Ich bin zuversichtlich, auf meine Hand- und Fingergelenke zu achten, (auch dann) wenn ich . . . *I am confident that I can care for my joints, (even) when I . .*	Sehr überzeugt *Very confident*	Eher überzeugt *Quite confident*	Eher nicht überzeugt *A little confident*	Gar nicht überzeugt *Not at all confident*	Kommt nicht vor *Not applicable*
einen leichten Gegenstand hebe *lift a light object*					
schlecht gelaunt bin *am in a bad mood*					
koche *cook*					
beobachtet werde *am being watched*					
einkaufe *shop*					
keine Zeit habe *have no time*					
Schreibe *write*					
Nicht danach zumute sein *do not feel like it*					
einen leichten Gegenstand trage *carry a light object*					
sehr beschäftigt bin *am very busy*					

References

1. Bandura A. Self-efficacy: towards a unifying theory of behaviour change. Psychol Rev 1977;84:191-215.
2. Lorig K, Chastain RL, Ung E, Shoor S, Holman HR. Development and evaluation of a scale to measure perceived self-efficacy in people with arthritis. Arthritis Rheum 1989;32(1):37-44.
3. Keefe FJ, Lefebvre JC, Kerns RD, Rosenberg R, Beaupre P, Prochaska J, et al. Understanding the adoption of arthritis self-management: stages of change profiles among arthritis patients. Pain 2000;87(3):303-13.
4. Taal E, Rasker J, Wiegman O. Patient education and self-management in the rheumatic diseases: a self-efficacy approach. Arthritis Care Res 1996;9:229-38.
5. Taal E, Rasker JJ, Seydel ER, Wiegman O. Health status, adherence with health recommendations, self-efficacy and social support in patients with rheumatoid arthritis. Patient Educ Couns 1993;20(2-3):63-76.
6. Brekke M, Hjortdahl P, Kvien TK. Self-efficacy and health status in rheumatoid arthritis: a two-year longitudinal observational study. Rheumatology (Oxford) 2001;40(4):387-92.
7. Brekke M, Hjortdahl P, Kvien TK. Changes in self-efficacy and health status over 5 years: a longitudinal observational study of 306 patients with rheumatoid arthritis. Arthritis Rheum 2003;49(3):342-8.
8. Barlow JH, Turner AP, Wright CC. Long-term outcomes of an arthritis self-management programme. Br J Rheumatol 1998;37(12):1315-9.
9. Hammond A, Bryan J, Hardy A. Effects of a modular behavioural arthritis education programme: a pragmatic parallel-group randomized controlled trial. Rheumatology (Oxford) 2008;47(11):1712-8.
10. Lorig KR, Sobel DS, Ritter PL, Laurent D, Hobbs M. Effect of a self-management program on patients with chronic disease. Eff Clin Pract 2001;4(6):256-62.
11. Heiberg T, Finset A, Uhlig T, Kvien TK. Seven year changes in health status and priorities for improvement of health in patients with rheumatoid arthritis. Ann Rheum Dis 2005;64(2):191-5.
12. Hammond A, Lincoln N. Development of the Joint Protection Behavior Assessment. Arthritis Care Res 1999;12:200-7.
13. Hammond A, Lincoln N, Sutcliff L. A crossover trial evaluating an educational-behavioural joint protection programme for people with rheumatoid arthritis. Patient Educ Couns 1999;40:1044-51.
14. Hammond A, Freeman K. The long-term outcomes from a randomized controlled trial of an educational-behavioural joint protection programme for people with rheumatoid arthritis. Clin Rehabil 2004;18:520-8.
15. Hammond A, Freeman K. One-year outcomes of a randomized controlled trial of an educational-behavioural joint protection programme for people with rheumatoid arthritis. Rheumatology (Oxdford) 2001;40:1044-51.
16. Cordery J, Rocchi M. Joint Protection and Fatigue Management. In: Rheumatologic Rehabilitation: Assessment and Management. Bethesda: The American Occupational Therapy Association, Inc; 1998. p. 279-322.
17. Basler H, Herda C, Keller S, Ridder K. Selbstwirksamkeitserwartung, Entscheidungsbalance und rückenbewusstes Verhalten zur Prävention von Rückenschmerz. Z Med Psychol 1998:149-57.
18. Marcus BH, Selby VC, Niaura RS, Rossi JS. Self-efficacy and the stages of exercise behavior change. Res Q Exerc Sport 1992;63(1):60-6.
19. Linacre J. Sample size and item calibration stability. Rasch Mes Trans 1994;7:328.
20. Prevoo M, van 't Hof M, Kuper H, van Leeuwen M, van de Putte L, van Riel P. Modified disease activity scores that include twenty-eight-joint counts. Development and validation in a prospective longitudinal study of patients with rheumatoid arthritis. Arthritis Rheum 1995;38:44-48.
21. Brühlmann P, Stucki G, Michel B. Evaluation of a German version of the physical dimension of the Health Assessment Questionnaire in patients with rheumatoid arthritis. J Rheumatol 1994;21:1245-9.

22. Andrich D. Rasch Models for Measurement. Newbury Park, London, New Delhi: Sage Publications, Inc; 1988.
23. Rasch G. Probabilistic Models for Some Intelligence and Attainment Tests. Chicago: University of Chicago Press; 1960 (reprint 1980).
24. Tennant A, Conaghan PG. The Rasch measurement model in rheumatology: What is it and why use it? When should it be applied, and what should one look for in a Rasch paper? Arthritis Rheum 2007;57(8):1358-62.
25. Tennant A, Pallant J. Unidimensionality matters! (a tale of two Smiths?). Rasch meas trans 2006;20:1048-51.
26. Smith E. Detecting and evaluating the impact of multidimensionality using item fit statistics and principal components analysis of residuals. J Appl Meas 2002;3:205-231.
27. Streiner D, Norman G. Health Measurement and Scales. Oxford: Oxford University Press; 1995.
28. Hammond A. Joint protection behavior in patients with rheumatoid arthritis following an education program: a pilot study. Arthritis Care Res 1994;7:5-9.
29. Niedermann K, Forster A, Hammond A, Uebelhart D, de Bie R. Development and validation of a German version of the joint protection behavior assessment in patients with rheumatoid arthritis. Arthritis Rheum 2007;57(2):249-55.
30. Bezruczko N. Raw score nonlinearity obscures growth. Rasch Measurement Transactions 2004;18(2):973-974.
31. McHorney CA, Tarlov AR. Individual-patient monitoring in clinical practice: are available health status surveys adequate? Qual Life Res 1995;4(4):293-307.
32. Mueller A, Hartmann M, Mueller K, Eich W. Validation of the arthritis self-efficacy short-form scale in German fibromyalgia patients. Europ J Pain 2002;7(2):163-71.
33. Tonge B, King N, Klimkeit E, Melvin G, Heyne D, Gordon M. The Self-Efficacy Questionnaire for Depression in Adolescents (SEQ-DA). Development and psychometric evaluation. Eur Child Adolesc Psychiatry 2005;14(7):357-63.
34. Sallis J, Pinski R, Patterson T, Nader P. The development of self-efficacy scales for health-related diet and exercise behaviors. Health Edu Res 1988;3:283-92.
35. Miller GA. The magical number seven plus or minus two: some limits on our capacity for processing information. Psychol Rev 1956;63(2):81-97.
36. Molenaar N, editor. Response-effects of 'formal' characteristics of questions. New York: Academic 1982.
37. Hawthorne G, Mouthaan J, Forbes D, Novaco RW. Response categories and anger measurement: do fewer categories result in poorer measurement?: development of the DAR5. Soc Psychiatry Psychiatr Epidemiol 2006;41(2):164-72.
38. Katz JN, Larson MG, Phillips CB, Fossel AH, Liang MH. Comparative measurement sensitivity of short and longer health status instruments. Med Care 1992;30(10):917-25.
39. Hewlett S, Cockshott Z, Kirwan J, Barrett J, Stamp J, Haslock I. Development and validation of a self-efficacy scale for use in British patients with rheumatoid arthritis (RASE). Rheumatology (Oxford) 2001;40(11):1221-30.
40. Siegert RJ, Tennant A, Turner-Stokes L. Rasch analysis of the Beck Depression Inventory-II in a neurological rehabilitation sample. Disabil Rehabil 2009:1-10.

Chapter 6

Effects on communication and treatment outcome of PRISM (Pictorial Representation of Illness and Self Measure), a novel visualisation technique. Two case studies

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Supplemental material

Abstract

Objective: The Pictorial Representation of Illness and Self Measure (PRISM) is a novel and brief interactive hands-on-tool. PRISM maps the relationships between illness and other aspects of the patient's life. This enhances therapeutic potential within a routine clinical care setting.
Methods: Two cases to exemplify the use of PRISM in rheumatoid arthritis (RA) patients during occupational therapy (OT).
Results: In case 1, PRISM facilitated the identification and changes of important life aspects, decreasing perceived suffering from illness.
In case 2, PRISM offered a technique for the patient to confront important aspects of her own life and better accommodate personal needs.
Conclusions: The application of PRISM was simple and powerful. It optimized and accelerated therapeutic processes and enhanced patient-therapist communication of individual aspects of illness.
Practice Implications: We recommend the use of PRISM for daily clinical OT-practice.

Introduction

The progressive loss of physical health experienced by people with chronic rheumatic diseases forces them to make changes in life perspectives and aspirations. This so-called 'response shift' (1) may have marked effects on quality of life. There is evidence that individual beliefs and attitudes better predict a patient's ability to cope with the illness than disease severity, age or gender (2). Unsuccessful coping results in suffering, i.e. 'severe distress associated with events that threaten the intactness of a person' (3). Thus, suffering is related to restrictions or losses in aspects of life that are most salient for that person.

The Pictorial Representation of Illness and Self Measure (PRISM) was developed and validated to measure a person's suffering caused by illness and/or pain, quantitatively and qualitatively (2, 3). However, an extension of the tool (PRISM+) can be used to assist in characterizing other important aspects of a patient's life (4), offering novel opportunities for therapeutic goal setting and visual insight into individual coping processes (2). PRISM+ may be performed in 5-15 minutes during routine clinical encounters.

PRISM facilitates narrative-based practice (NBP) (5), which aims to focus on the person rather than symptoms or illness. Each patient develops a narrative to make sense of the illness experience, and eliciting such narratives is an integral part of person-centred medicine (8). In routine practice, there is little time to devote to such narratives, but PRISM+ facilitates this. Earlier work detected the use of PRISM+ to accelerate therapeutic processes and enhancing patient-therapist communication of individual aspects of illness, the patient's life and resources (4). In this paper we present the use of PRISM+ with two RA patients referred to occupational therapy (OT),

Methods

The Occupational Therapy (OT) Intervention

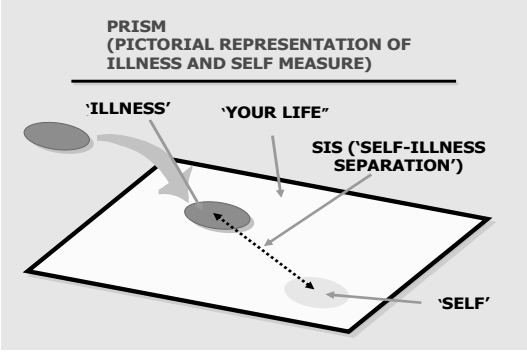
JP behaviour improves function and reduces pain and thus is an active coping strategy to improve daily tasks' and role performance (6). JP education therefore needs to be individualized to the patient's tasks and life situation.

The PRISM tasks

The patient is shown a white A4-size board with a fixed yellow disk (7cm in diameter) at the bottom right corner. (S)he is asked to imagine that the board represents his/her current life and the disk represents her/his *Self*. The person is then handed a red disk (5 cm in diameter) that represents the *Illness* and asked to put this disk where it reflects the current importance of the illness in his/her life. The distance (in centimetres) between the centres of the *Illness* and *Self* disks is the Self-Illness Separation (SIS), (range 0-27 cm, with a smaller distance indicating higher importance) (Figure 1). In PRISM+ (4), further disks, similar to the illness disk but different colours, can be used to represent

other important aspects of the patient's life (e.g. work, family, hobbies, friends) to visually summarize relationships between the illness and these aspects. The SIS is used accordingly.

Figure 1: Use of PRISM standard task



Results

The characteristics of the two cases are presented in Table 1.

Table 1: Patients' demographic and clinical characteristics at first assessment

	Case 1: Mr. M	**Case 2: Mrs. S**
Age	44 years	52 years
Family status	Married, no children	Married, two adolescent children (14 and 17 years)
Home circumstances	Own house, small garden	Own (big) house, garden
Job (hours/week)	Salesman (45 hours)	Office aid (8 hours)
Onset of RA	2004	1993
ACR functional class	1	4
Rheumatoid nodules	No	Yes
Rheumatoid factor	Yes	Yes
Erosions	No	Yes
Drug therapy	DMARD: Methotrexate NSAID: Diclofenac	DMARD: Etanercept; NSAID: Celecoxib
DAS28	2.16	1.11
HAQ score	0.63	2.25
RADAI	1.7	1.5
Arthritis pain (RADAI)	4	1
General health (RADAI)	4	9
Anxiety, depression (HADS)	2 /21, 2/21	3 /21, 4/21

DMARDs = disease-modifying anti-rheumatic drugs; NSAIDs = non-steroidal anti-inflammatory drugs; DAS28 = Disease Activity Score in 28 joints; HAQ = Health Assessment Questionnaire; RADAI = RA Disease Activity Index; HADS = Hospital Anxiety and Depression Scale.

Case 1: Mr. M. was referred to OT due to bilateral wrist pain. He worked full-time, but hardly did any domestic work, except for feeding his cats. He called himself 'an exercise grump' and mentioned playing music (accordion, keyboard) as leisure activities. Mr. M. had five JP education sessions, mainly practicing JP principles and problem solving, where the therapist included the PRISM tasks in the assessment and intervention.

Session 1: Mr. M. put the illness disk not far from *the Self* (SIS = 12 cm) (Figure 1a), commenting he felt very disabled due to RA, as pain was always present, thus reminding him of his illness. He perceived himself as different from who he was before his RA became symptomatic.

Session 2: using PRISM+, Mr. M. placed four disks representing *personal care, spouse/friends, work* and *leisure activities* (Figure 2a). When asked which of these could be a resource, he mentioned past leisure activities, especially sailing and riding his motorbike. He confessed that because of his illness the boat had been sold and motorbike and bicycle were getting dusty in the cellar and he even abandoned his dream to ride his Harley Davidson in the Grand Canyon. His wife tried to motivate him to undertake physical activity, but he did not like going for walks with her, as she was supposedly too fast for him and he was even less motivated to go out alone. After discussion, *biking* (the bike, as preparation for riding the motorbike) was defined as the most important resource to reactivate (actually placed at 23.5 cm from *Self*) and repairing the bike was his homework task.

Session 3: Mr. M. placed the *biking* disk much closer to the *Self* (12.5 cm) and reported he prepared the bike - to his wife's surprise - but had not yet used it. His homework was to go on a small bike excursion.

Session 4: the distance between *Self* and *biking* had hardly changed (12 cm). However, SIS had increased substantially, to 22 cm. Although he had not had much time, he had been walking with his wife and cycling without problems handling brake or gears. He felt his dream of Grand Canyon was still possible and he was going to look for a special motorbike clutch to enable him to better handle his motorbike.

2 months later at session 5, the situation was very similar, SIS was 22 cm and distance between *Self* and *biking*' (Figure 2b) was 13 cm, because he still felt far from his dream. However, he had ordered a modified clutch and started to cycle with his wife, being faster than her.

He was convinced he would one day realize his "American Dream", and was now determined that RA should interfere as little as possible with the quality of his life.

Case 2: Mrs. S. had severe joint destruction due to RA, mainly in her hands and feet. She was only able to do light domestic work, needing a cleaner's help. She also worked as an office aid in her husband's business and as a volunteer in a self-help organization. Her favourite leisure activities were playing cards and reading. Focus of her JP education sessions was on workplace organization and pacing daily tasks. The therapist applied the PRISM tasks.

Session 1: PRISM revealed an SIS of 6 cm (Figure 2c). Mrs. S. commented that RA was a constant in her life and perceived it as physically and psychologically constricting, even when she was well.

Session 2: using PRISM+, Mrs. S. placed disks representing *personal care*, *spouse/family*, *work* and *leisure activities* (Figure 2c), mentioning she would prefer to share her leisure activities with her family, especially her husband (8 cm from *Self*), to feel closer to him. Therapist and patient agreed on *caring for relationship with husband* as resource and homework was to discuss this with him.

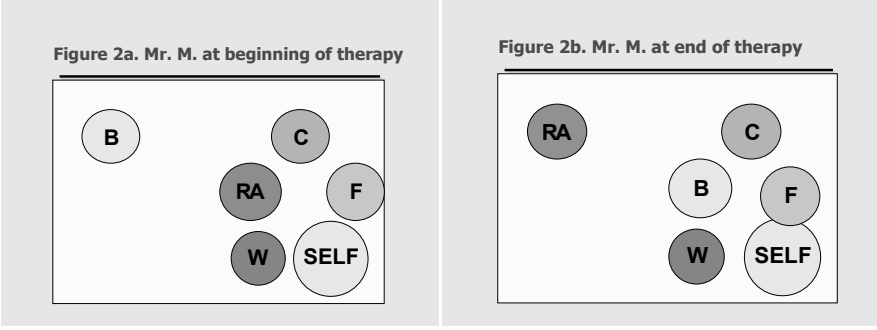
Session 3: Mrs. S. reported her husband did not want to share her hobbies holding that each spouse should have their own activities. She accepted this and changed her resource activity to *caring for my own needs*, placing an additional disk at 9 cm. She admitted that she would prefer to work independently from her husband, earn her own money and obtain more recognition from her family. Mrs. S. mentioned that her husband once said she was expensive; due to her illness she needed not only therapies and special devices, but also a cleaner, regular hairdresser, manicure and pedicure. Due to the finances needed for her care, it was also impossible for him to retire earlier. Mrs. S. often felt guilty and a burden to her family. Homework was to fill out a week's diary allowing analysis of her daily burden and tasks, but also to distinguish between duties and her own chosen activities.

Session 4: Mrs. S. put her illness disk right at the centre (SIS = 0 cm), as she had a substantial deformity in her right forefoot with ulcerations at sites of high focal pressure, and the *own needs* disk was put at 8 cm. Her diary revealed she did much for her family, but she reflected that she received little recognition for her efforts, and was only offered help when she asked for it. Her homework was to use the diary as the basis for dialog with her husband and children. The therapist discussed which tasks her daughters could help with, e.g. cooking, and encouraged her to ask them for help, not because of RA but because it should be normal for children to help.

Session 5 two months later: SIS was 7 cm as Mrs. S. perceived her illness as always present in her life, implying severe physical and psychological constrictions. However, she perceived progress in dealing with her circumstances. She started to take more time for herself, putting the *caring for my own needs* disk at 2 cm (Fig.2d). Due to recent foot surgery it was easier for her to look after herself and her situation highlighted by PRISM+ and the diary increased her resolve to be firmer with her family about her own needs.

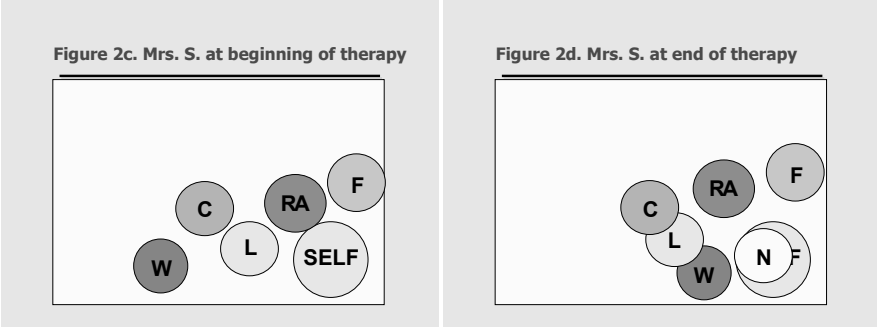
Figure 2: PRISM and PRISM+ in Case 1 and Case 2

Case 1: Changes in PRISM and PRISM+



C=Personal Care F=Family/Friends W=Work B=Biking

Case 2: Changes in PRISM and PRISM+



C=Personal Care F=Husband/Family W=Work L=Leisure Activities N=Own Needs

Discussion and conclusion

Discussion

The two case studies illustrate the benefits of using PRISM during routine clinical assessments to provide a visual summary of the burden of illness and its impact on important aspects of a person's life. Using PRISM can have a marked effect on therapeutic processes. In case A, PRISM+ allowed patient and therapist to gain a good impression of the overall impact of the illness much more quickly than would have been possible by discussion alone. PRISM+, inviting the patient to decide what other aspects of Personhood should be represented and placing these appropriately, allows relationships between these aspects to be 'mapped'. Again, PRISM+ allows these relationships to be summarized much more rapidly than within a conventional narrative. This process encourages patient - and clinicians of any profession - to view the illness in a biopsychosocial context, rather than seeing it as an isolated (biological) phenomenon. For Mr. M., as for most other people with a chronic illness, any attempt to reduce the burden of illness (beyond the use of specific medical interventions) requires changes in other

aspects of one's life. PRISM+ facilitated the identification and monitoring of these life aspects. PRISM+ not only enhanced the patient's awareness of change but also increased his sense of control over his life and circumstances.

In case B, PRISM+ offered a powerful and simple technique for Mrs. S. to look at herself and confront important aspects of her own life. As in Mrs. S.'s case, it is not uncommon for the experience of chronic illness to reduce self-esteem (7) and family attitudes can sometimes reinforce such lowered self-esteem. Using PRISM+ made Mrs. S. aware that her personal needs were not being accommodated and this became a turning point, not only in the therapeutic intervention, but also more generally in her life.

Conclusion

The PRISM standard task offers clinicians a simple and brief method to assess suffering. PRISM+ offers a method of organizing and communicating information that is very complex and allows the illness to be "mapped" in a biopsychosocial context. PRISM+ helps and accelerates the patient's narrative by "starting at chapter 10". Patient and clinician have the opportunity to understand the patient's illness experience, identify and work on important aspects of the patient's life, and measure changes. This leads not only to more comprehensive and focused interventions, but also enhances the patient's sense of self-mastery.

Practice Implication

As the use of PRISM is easy and the clinical use is time saving and enriching the therapeutic process with salient information we recommend its use for daily clinical OT-practice.

References

1. Sprangers, M. and C. Schwartz, Integrating response shift into health-related quality of life research: a theoretical approach. Soc Sci Med, 1999. 48: p. 1507-1515.
2. Buchi, S., et al., Graphic representation of illness: a novel method of measuring patients' perceptions of the impact of illness. Psychotherapy & Psychosomatics, 1998. 67(4-5): p. 222-25.
3. Buchi, S., et al., Preliminary validation of PRISM (Pictorial Representation of Illness and Self Measure) - a brief method to assess suffering. Psychotherapy & Psychosomatics, 2002. 71: p. 333-41.
4. Buchi, S. and T. Sensky, PRISM: Pictorial Representation of Illness and Self Measure. A brief nonverbal measure of illness impact and therapeutic aid in psychosomatic medicine. Psychosomatics, 1999. 40(4): p. 314-20.
5. Frank, A., The Wounded Storyteller, Body, Illness and Ethics. 1995, Chicago: The University of Chicago Press.
6. Hammond, A., N. Lincoln, and L. Sutcliff, A crossover trial evaluating an educational-behavioural joint protection programme for people with rheumatoid arthritis. Patient Educ Couns, 1999. 40: p. 1044-51.
7. Morley, S., C. Davies, and S. Barton, Possible selves in chronic pain: self-pain enmeshment, adjustment and acceptance. Pain, 2005. 115(1-2): p. 84-94.

Chapter 7

Effectiveness of individual resource-oriented joint protection education in people with rheumatoid arthritis. A randomized controlled trial

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In press, Patient Education and Counseling

Abstract

Objective: The modern joint protection (JP) concept for people with rheumatoid arthritis (RA) is an active coping strategy to improve daily tasks and role performance by changing working methods and using assistive devices. Effective group JP education includes psycho-educational interventions. The Pictorial Representation of Illness and Self Measure (PRISM) is an interactive hands-on-tool, assessing a) the individual's perceived burden of illness and b) relevant individual resources. Both issues are important for intrinsic motivation to take action and change behaviour. This study compared individual conventional JP education (C-JP) with PRISM-based JP education (PRISM-JP).
Methods: An assessor-blinded multicentre randomized controlled trial, including four JP education sessions over three weeks, with assessments at baseline and 3 months.
Results: In total 53 RA patients participated. At 3 months, the PRISM-JP (n=26) participants did significantly better compared to the C-JP participants (n=27) in JP behaviour ($p=0.02$ and $p=0.008$ when corrected for baseline values), Arthritis Self-Efficacy (ASES $p=0.015$) and JP self-efficacy (JP-SES $p=0.047$). Within-group analysis also showed less hand pain ($p<0.001$) in PRISM-JP group.
Conclusion: PRISM-JP more effectively supported learning of JP methods, with meaningful occupations, resource activation and self-efficacy acting as important mediators.
Practice implications: PRISM improved patient-clinician communication and is feasible for occupational therapy.

Key words: rheumatoid arthritis, joint protection, patient education, self-efficacy, occupational therapy, randomized controlled trial

Introduction

Hand joint protection (JP) education is a standard occupational therapy intervention in the multidisciplinary management of people with rheumatoid arthritis (RA) (1). Hand involvement is one of the major problems from the patients' perspective (2) and limits them in relevant activities and social participation (3). The JP concept has developed to a self-management approach 'to improve daily tasks and role performance through the use of alternative working methods and assistive devices, which may thus enhance perceptions of control and improve psychological status' (4).

The development of JP aims also implied use of other teaching methods. Traditional teaching methods such as use of written information, demonstrations, supervised practice and visual aids were successful in providing knowledge and skills (5). However the aims of behavioural change and self-management require other strategies (6). Various studies demonstrated the effectiveness of JP as a self-management strategy, provided that psycho-educational interventions are applied as they facilitate behavioural change with respect to JP use more successfully (4, 7, 8). JP is often provided in a one-to-one setting, however it is currently unclear, whether the effects of psycho-educational JP education in group settings are applicable to an individual approach.

Self-management requires the patients' involvement and responsibility for the day-to-day management of their illness (9). There is evidence that individual beliefs and attitudes of patients are better predictors of patients' abilities to cope with the illness than disease severity, age or gender (10). Unsuccessful coping results in suffering that is thus determined less by the disease itself than by its meaning to the individual (11).

The Pictorial Representation of Illness and Self Measure (PRISM) is a brief interactive hands-on tool, requiring simple instructions and little time. The standard PRISM task was developed to quantitatively and qualitatively assess a person's suffering caused by an illness and/or pain (12, 13). This perceived impact of disease is related to restrictions or losses in aspects of life that are most salient for that person (14). An extension of the tool (PRISM+ task) visually summarises relationships between illness and other important aspects of the patient's life (e.g. work, family, hobbies, friends) (15). This stimulates therapeutic focus shift from illness to the individual and his/her strengths and perception of important life aspects as resources. The PRISM+ task refers to Hobfoll's resource conservation model, which related the ability to cope with stress to the ability to conserve or substitute resources of one's life (16).

In this study, PRISM was used to guide an individualised JP intervention, as typical practice in Switzerland is one-on-one JP education. In routine clinical care PRISM has demonstrated high therapeutic potential. The PRISM tasks apply a client-centred approach and help to identify meaningful occupations (3). It was assumed that this would have a strong effect on patients' learning motivation and on improving transfer of JP education to daily life (17).

The study aim was to evaluate whether individualised, resource-oriented JP education (PRISM-JP) in RA patients facilitates JP acquisition and adherence more successfully, compared to conventional JP education (C-JP).

Methods

Patients

Patients were recruited by rheumatologists of four rheumatology departments in German-speaking regions of Switzerland. They were eligible when: diagnosed with RA according to ACR (American College of Rheumatology) guidelines (18); in ACR functional class ll (limited in avocational activities), lll (limited in vocational and avocational activities) or IV (limited in usual self-care, vocational, and avocational activities) (19) associated with difficulties and/or pain in hands, justifying occupational therapy, and had sufficient German language skills. Severe finger, hand and shoulder joint deformities were exclusion criteria, as these can lead to difficulty performing common JP methods and require more idiosyncratic solutions.

Patients were asked to participate in a study aimed at evaluating two different educational approaches within occupational therapy, but they were not informed that focus was on JP behaviour. Ethic approval was obtained in the three regions involved and patients provided informed consent prior to participation. The study was registered in Clinical.Trials.gov.

Design and randomization

An assessor-blinded, multicentre randomized controlled trial was conducted.
After mailing the informed consent to the study centre, participants were randomly assigned to one-on-one JP education, either C-JP or PRISM-JP, by sequentially numbered, concealed treatment allocations prepared in advance. Randomization was stratified for each hospital and a four-block sequence (20) was performed to ensure balanced allocation of participants to the two groups.

After randomization, the study centre contacted the patients and explained the assessment procedure that involved video recording of performing a task, e.g. no recording of face and voices, to minimize the risk of refusal. The PRISM-JP participants were sent a letter to support adherence to program and JP behaviour (4).

Interventions

In each of the four centres, two experienced rheumatology occupational therapists (OTs) provided the C-JP or the PRISM-JP. When preparing this study, a consensus meeting with all OTs involved was held to standardise the JP education of the four participating institutions. There was little disagreement on content and delivery, as representing typical practice in Switzerland. Both C-JP and PRISM-JP were defined as four 45-minute sessions within 3 weeks.

Conventional JP education

C-JP consisted of the standardised JP education content by the use of traditional teaching methods. This was summarised in a short manual: oral and written information about RA and JP principles (21); demonstrations and supervised practice of hand JP methods, mostly in a kitchen activity, and demonstration of appropriate assistive devices. 'Preparing instant coffee' was the activity assessed as primary outcome and therefore not allowed as practicing example. OTs documented in written form any additional intervention (e.g. home exercise, final provision of assistive devices, splints)

PRISM-based JP education

The PRISM-JP education also consisted of the standardised JP education, but was much more individualised, and based on the PRISM tasks (PRISM / PRISM+), the theories of social learning (22, 23) and self-management (24). The OTs providing PRISM-JP were trained by two researchers (KN, SB) to assess the perceived burden of illness, to elucidate important resources and to set personally relevant therapeutic goals by means of PRISM / PRISM+ and to understand the applied theories of social learning and self-management. While the study was ongoing, these OTs participated in three supervision meetings to ensure correct application of PRISM.

Application of PRISM (12) and PRISM+(15): When performing the *PRISM task*, the patient is shown a white A4-sized board with a fixed yellow disk (7cm in diameter) at the bottom right corner. S(he) is asked to imagine the board represents his/her life as it currently is, and the disk his/her "Self". The person is then handed a red disk, 5 cm in diameter, representing his/her "Illness" and asked where (s)he would put the Illness disk to reflect the burden of illness in his/her life at present. The quantitative measure is the "Self-Illness Separation" (SIS), the distance between the centres of the "Illness" and the "Self" disks (range 0-27 cm), with a smaller distance indicating higher impact of the illness (Figure 1a) (12). For the *PRISM+ task* further disks, similar to the illness disk but of different colours, can be used to represent a patients' resources (e.g. leisure activities, family/friends, work). The SRS (Self-Resource-Separation) is used accordingly, i.e. the distance between the centres of a "Resource" and the "Self" disks (range 0-27 cm). However, the SRS has to be interpreted differently than the SIS: larger distances indicate a less positive impact of the resource, while smaller distances indicate a more positive impact (Figure 1b). The sessions' contents below describe the application of the PRISM tasks in the PRISM-JP education in detail.

Figure 1: Application of PRISM task and PRISM+ task

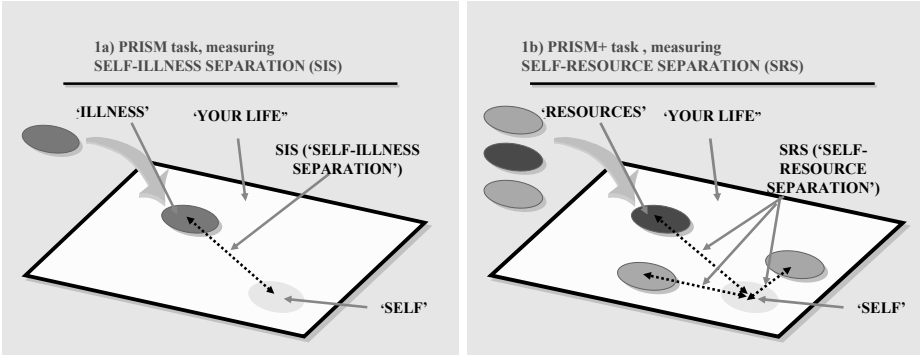

Fig. 1a) Self-Illness Separation (SIS) = measured distance between 'Self' and 'Illness' - a smaller SIS indicates a higher (negative) impact of the illness.
Fig. 1b) Self-Resource Separation (SRS) = measured distance between 'Self' and 'Resource'; a smaller SRS indicates a higher (positive) impact of the resource. In this example, the green resource (e.g. representing family/friends) is perceived as the resource with the highest positive impact, the blue resource (e.g. representing work) is perceived as the resource with the lowest positive impact.

Application of theories of social learning and self-management: Self-efficacy, i.e. one's perceived ability to perform a behaviour, and outcome-efficacy, i.e. belief that a behaviour is beneficial, are central concepts of social learning theory. Both are important mediators of performance (22). Self-efficacy enhancing methods such as direct experience (in individually meaningful tasks and resources) and positive feedback mechanisms were included to support internal motivation as a central trigger for behaviour change and better self-management.

The PRISM-JP education was allocated to sessions 1 to 4, whereas the C-JP education was not allocated to specific sessions.

In *session 1,* the PRISM task was used to assess perceived burden of illness caused by the RA or pain and identify individual JP education goals. After placing the illness disk SIS was measured and the patient was asked to describe in which activities and why problems occurred. By this, relevant tasks were identified and used to link the JP education to individually important tasks and activities. This client-centred approach helped to select individually meaningful rather than purposeful occupations in conventional JP education, such as household or self-care activities (3). Positive goal formulation (what to do) rather than negative (what to prevent) was emphasized.

In *session 2,* The PRISM+ task helped to find the most important individual resource. Patients were asked what activities were most important to them. They chose one single resource with a most positively perceived impact, which they wanted to foster during therapy such as listening/playing music or going to cinema and meeting friends. This resource was deliberately selected not to be in any connection to illness related problems and JP activities. By this, JP education usually related with the disease and its negative aspects, was linked with positive goals and memories to enhance patients' motivation for collaboration (15). The aim was to improve the positive impact of

the selected activity which was expressed in a decrease of the SRS, i.e. the distance between the "Resource" and the "Self" disks.

In *sessions 3 and 4*, the selected resource was evaluated and reinforced.

JP education and practice were part of every session. They became progressively complex, starting with self-monitoring of hand use and activities causing pain and difficulties; proceeding onto selecting one or several JP principle(s) to applying (referring to life areas defined in session 1) and practicing JP methods within individually selected complex activities and discussing and applying transfer of JP methods to other activities. Energy conservation, the balance between activity and rest was addressed in session 4.

Homework tasks consisted of reading booklets about RA and JP methods, edited by the Swiss League Against Rheumatism, practicing selected JP methods and the same complex JP activity, applying selected JP principles to various situations in short- and mid-term (between session 4 and follow-up assessment).

Goal setting and self-monitoring were important integral parts of homework. After agreeing on homework tasks and setting goals for the next session, patients wrote them in their diary and were encouraged to self-monitor their activities. Their perceived confidence to perform their homework was assessed on a 0-10 VAS; when confidence was graded below 7 points, reasons for this and possible solutions were immediately discussed. Homework and the experienced facilitators of and barriers to JP use were evaluated at the beginning of the subsequent session.

Social support: Participants were encouraged to discuss the reading material with their partners and invite them to participate in session 4.

Assessment procedure

Two comprehensive assessments at baseline, i.e. before JP session 1 (T0) and at 3-month follow-up (T1) were administered. JP behaviour and pain was also monitored immediately after session 4 (T1).

Outcomes and outcome measures

Primary outcome measure

Joint protection behaviour: was evaluated using the German version of the Joint Protection Behaviour Assessment D-JPBA-S (25). It assesses use of JP methods while performing nine tasks required when preparing instant coffee (e.g. turning tap, carrying pan, opening coffee jar). Patients were kept blinded about the true purpose of the video recording to ensure habitual performance, light conversation was continued to distract from paying conscious attention to hand use.

Video recordings were transferred to Pinnacle Instant CD/DVD 11.0 software (Pinnacle systems, Mountain View, CA) and edited in unsorted sequence on CDs for assessment to ensure blinding to patients' treatment allocation and time-point of recording. One rheumatology OT rated all assessments following the instructions of the D-JPBA-S manual.

Secondary outcome measures

Psychological status. The Arthritis Self-efficacy Scale, German Version (A-SES-D), an 8-item self-administered questionnaire (26) and the JP self-efficacy scale (27), a 10-item self-administered questionnaire were used to assess arthritis and behaviour specific self-efficacy. The Hospital Anxiety and Depression Scale, German Version, (HADS-D) (28), was used to measure psychological distress. Scores of 8+ and 11+ have been suggested as indicative of a possible clinical state (e.g. suffering from emotional disorder) and a probable clinical state, respectively, for both anxiety and depression (29)

Hand status. Grip strength was measured using a Jamar hand dynamometer (30) at each video recording. Hand pain during moderate activity was assessed with a 0-10 VAS scale.

*Disease activity, u*sing the Disease Activity Score (DAS28), (31) and *drug therapy* were monitored.

Quality of life. The EUROHIS-QUOL 8, an 8-item WHO quality of life questionnaire assessing general quality of life (32) was used.

PRISM and PRISM+: Increasing SIS means less perceived burden of disease, decreasing SRS means better resource activation. As only the experimental intervention was based on the PRISM, these data are only available for this group.

Other data collected at baseline only

Patients' demographic and clinical characteristics were recorded.

Impairment of dominant hand: active Range Of Motion (ROM) was measured with goniometry; finger and wrist joint deformity were assessed using the Joint Alignment and Motion Scale (JAM) (33).

Physical functional ability: using the ACR functional classes (19) and the Health Assessment Questionnaire (HAQ) (34).

Self-perceived disease activity and typical RA symptoms such as pain and morning stiffness: using the Rheumatoid Arthritis Disease Activity Index (RADAI) (35).

Coping resources: Sense of Coherence (SOC), a 13-item self-administered questionnaire measuring the dimensions comprehensibility, manageability and meaningfulness regarded as stable person-related characteristics (36)

Statistics

Sample size calculations (37) were based on data from the D-JPBA-S validation study (25). A minimum of 22 participants per group was needed to detect a 20% difference in JP behaviour scores, assuming a mean change of 5.5 points (SD 3.7) on a linear scale, power of 90% and significance level of 0.05. To reach the same even number over the 4 centres, including a 20% drop out rate, 56 patients would be necessary.

Rasch analysis was performed on the D-JPBA-S and JP-SES data to convert the ordinal raw data to interval scaled data (25). For each questionnaire, the data of the different time points were transformed within the same frame of reference (38).

The interval scaled data obtained by this procedure, allowed for appropriate statistical procedures, i.e. unpaired t-tests for between-group comparisons, paired t-tests for within group comparisons at 3 months and linear regression analysis. Mann-Whitney U-tests and Wilcoxon signed ranks tests were applied for ordinal data to compare between-groups and within-groups, respectively.

The relationship between change of primary outcome variable and predictor variables was analyzed by linear regression analysis (analysis of absolute change). Additionally, absolute change was calculated, correcting for the initial value of the primary outcome variable.

Intention-to-treat analysis was applied; missing data of one patient were substituted with mean values of her group.

Results

A total of 54 participants were recruited over a period of approximately 2 years. The distribution over the hospitals was 14 (7 randomized to C-JP, 7 to PRISM-JP), 13 (6 C-JP, 7 PRISM-JP) and 26 (12 C-JP, 13 PRISM-JP). One hospital recruited only 1 patient (C-JP) within 6 months and stopped study participation when the trained OT changed job. As one patient (PRISM-JP) dropped out after randomization but before assessments, 53 patients remained available for analysis. The participants of the two groups were well matched in relation to demographic and clinical data (Table 1). The average age and disease duration of the PRISM-JP patients were higher and thus the average professional work frequency, including weekly working time, was lower compared to the controls.

In both groups, the rate of patients on biologicals (anti-TNF, Rituximab) disease-modifying anti-rheumatic drugs (DMARDs), non-steroidal anti-inflammatory drugs (NSAIDs), glucocorticoids and analgetics was similar. About one-third of the patients in both groups were on a combination therapy of biologicals and DMARDs. All except one experimental patient attended all four JP sessions. This patient did not attend session 3, but filled out the questionnaires.

The primary and secondary outcome variables are presented in Table 2. Within-group analysis showed that both groups improved with respect to the use of JP methods ($p<0.001$) and pain ($p<0.001$) at session 4 (T1) and at the 3-months follow-up (T2) compared to their baseline values, except increased pain ($p \leq 0.01$) at T1 in the C-JP group.

After 4 sessions there were no differences between the treatment groups, however during the 2 months between therapy session 4 and the 3-months follow-up, the PRISM-JP group continued using JP methods, whereas the controls decreased the use of JP methods, resulting in a difference between groups at 3 months ($p=0.02$). When corrected for baseline JP behaviour (analysis of co-variance), group difference was more pronounced ($p=0.008$) (Table 3).

Table 1: Demographic and clinical baseline variables of study participants (n=53)

	Conventional JP education (n= 27)	**PRISM-based JP education (n=26)**
Gender (m/f)	5, 22	4, 22
Age (years)	53.44 (15.71)	62.08 (12.61)
Disease duration (years)	8.30 (9.75)	10.23 (7.64)
Patients < 65 years / with work ability	22 / 14 (64%)	17 / 10 (59%)
Weekly working hours	31.5 (12.31)	22 (14.22)
Patients with former OT / years since	4 / 5.75 (5.74)	6 / 8.17 (4.62)
ACR functional class (median/range)	2 (2-4)	2 (2-4)
Rheumatoid nodules (%)	3 (11%)	2 (8%)
Rheumatoid factor (%)	18 (66%)	20 (77%)
ANA (%)	15 (56%)	16 (62%)
Erosions (%)	15 (56%)	18 (69%)
Biologicals (anti-TNF, Rituximab)	8 (30%)	9 (33%)
DMARDs (no. of patients and %)	22 (82%)	20 (77%)
Steroids (no. of patients)	11 (41%)	13 (50%)
NSAIDs (no. of patients)	9 (33%)	11 (42%)
Analgetics	7 (26%)	2 (8%)
ROM wrist FLEX #	56.67 (17.38)	54.42 (22.51)
ROM wrist EXT #	49.70 (20.78)	47.50 (22.46)
ROM MCP FLEX #	78.52 (8.30)	75.77 (16.95)
ROM MCP EXT #	2.60 (19.92)	5.96 (13.79)
JAM wrist #, median (IQR) #	2 (1-2)	2 (1-2)
JAM MCP #, median (IQR) #	1 (1-2)	1 (1-2)
HAQ	1.18 (0.61)	1.08 (0.69)
RADAI	3.95 (2.41)	3.23 (2.18)
SOC	4.91 (1.08)	5.31 (0.86)

Values are the mean (SD), unless stated otherwise; NA = not available
ACR = American College of Rheumatology; ANA = anti-nuclear antibodies, DMARDs = disease-modifying anti-rheumatic drugs; NSAIDs = non-steroidal anti-inflammatory drugs; ROM = Range of Motion; JAM = Joint Alignment and Motion Scale; HAQ = Health Assessment Questionnaire; RADAI = Rheumatoid Arthritis Disease Activity Index SOC = Sense of Coherence
# of dominant hand

Table 2. Assessments at baseline, session4 and 3-months follow-up (means and standard deviations (SD))

	Conventional joint protection education (C-JP)			PRISM-based joint protection education (PRISM-JP)			Differences between groups (3-months follow-up)
	Baseline n=27	At session 4 n=27	3-months follow-up n=27	Baseline n=26	At session 4 n=26	3-months follow-up n=26	P-Values
D-JPBA-S	4.37 (4.25)	8.18 (3.56)***b)	7.75 (3.56)***b)	4.12 (5.01)	9.90 (3.57)***b)	9.99 (3.07)***b)	0.022*a) ; 0.008**a)
ASES-D	7.12 (1.59)		6.20 (6.13)*b)	6.51 (2.07)		7.49 (1.34)**b)	0.015*a)
JP-SES	17.71 (5.74)		19.32 (4.01)	18.02 (5.21)		21.64 (3.91)***b)	0.047*a)
HADS-A	4.33 (2.92)		4.92 (3.30)	6.92*a) (4.33)		6.79 (4.55)	0.09
HADS-D	4.33 (3.16)		4.24 (3.38)	5.27 (3.32)		4.81 (3.27)	0.53
Pain VAS	3.30 (2.90)	3.08 (3.01)***b)	3.50 (2.14)**b)	3.92 (3.12)	3.19 (3.09)***b)	3.12 (3.06)***b	0.76
Grip strength	15.50 (9.46)	15.17 (9.16)	17.93 (11.42)	14.88 (9.36)	15.79 (9.82)	15.68 (10.06)	0.46
EUROHIS-QOL-8 #	2.70 (0.67)		2.69 (0.70)	2.62 (0.49)		2.67 (0.53)	0.37
DAS28	3.72 (1.70)		3.29 (1.43)	3.70 (1.67)		3.30 (1.45)	0.99

D-JPBA-S: JP Behaviour Assessment; JP-SES: JP Self-efficacy; ASES-D: Arthritis Self-efficacy; VAS: Visual Analogue Scale; EUROHIS-QOL-8: Quality of Life 8 Item Index; HADS: Hospital Anxiety and Depressions Scale (-D, Depression and –A, Anxiety subscale); DAS28: Disease Activity Score in 28 joints; grip strength: measured of dominant hand (in kg)

Between-group analysis: *a) $p \leq 0.05$; **a) $p \leq 0.01$ when corrected for baseline values

Within-group analysis: *b) $p \leq 0.05$; **b) $p \leq 0.01$;***b) $p < 0.001$ (all compared to baseline)

All tests between groups are independent t-tests, except for EURO-Quol (Mann-Whitney-U test for ordinal data)

In the PRISM-JP group, 73% (19/26) increased D-JPBA-S scores by at least 20% (3.6 points) at T1 and 65% (17/26) did so at T2. In controls, 56% (15/27) improved 20% or more at T1 and 48% (13/27) at T2. Stepwise multiple linear regression analysis indicated that 74% of the larger improvement in the PRISM group could be explained by the (lower) baseline JP behaviour scores and the intervention (Table 3). The absolute changes in JP behaviour for Δ(T0 – T1) and Δ(T0 – T2) were 5.78 (SD 4.57) and 5.88 (SD 4.94) respectively, for the PRISM-JP group and 3.82 (SD 3.37) and 3.39 (SD 3.68) respectively, for the controls, resulting in a significantly larger absolute change in the PRISM-JP group (p=0.04, 95% CI -4.88 to -0.09). When taking the Smallest Detectable Difference (SDD) into account, as calculated in the D-JPBA-S validation study (25), substantially more participants of the PRISM-JP group increased their JP behaviour scores by more than 5.5 points (>30% improvement) compared to the controls: 14 patients (56%) vs. 9 patients (33%) at T1 and 16 patients (62%) vs. 9 patients (33%) at T2.

By T2, the PRISM-JP group had significantly better Arthritis Self-Efficacy (ASES) (p=0.03) and JP self-efficacy (JP-SES) (p=0.05) scores. Within group analysis revealed that the PRISM-JP group increased ASES (p=0.006) and JP-SES (p<0.001) whereas in the controls ASES scores decreased (p = 0.018).

The PRISM-JP group had higher HADS anxiety scores at baseline, representing more patients with elevated scores of 8+ and 11+ in anxiety. There were no differences in all other outcome variables between and within the groups before and after intervention.

Table 3: Main factors explaining larger changes in JP behaviour for PRISM group

Variables	B	SE B	Beta	t	Sig
Constant	6.30	0.72		8.76	0.000
Baseline JP behaviour	-0.67	0.09	-0.68	-7.16	0.000
Intervention	2.32	0.85	0.26	2.74	0.008

$R^2 = 0.74$

Sub-Analysis of PRISM-JP group

The perceived burden of disease did not decrease during the intervention and remained unchanged during the 2 months break, however the participants activated their selected resources constantly, resulting in a significant difference from baseline at T2 (p=0.03) (Table 4).

Table 4: PRISM measured perceived impact of illness (SIS) and impact of resource (SRS) (PRISM-JP group)

PRISM (measure)	Session 1	Session 2	Session 3	Session 4	3-months Follow-up
PRISM task (SIS)	12.60 (8.50)			11.78 (8.92)	13.60 (8.20)
PRISM+ task (SRS)		10.04 (7.19)	8.92 (5.65)	8.06 (5.14)	7.42 (3.99) p= 0.029* 95% CI = 0.29 to 5.03

SIS ("Self-Illness Separation"): an increasing SIS indicates lower impact of the illness
SRS ("Self-Resource-Separation"): a decreasing SRS indicates a more positive impact of the resource
Within group analysis (paired samples t-test) *p=≤ 0.05 (baseline (SIS) and session 2 (SRS) to 3-months follow-up)

Discussion and conclusions

Discussion

This study demonstrated that individualised, resource-oriented psycho-educational JP education (PRISM-JP) supported the acquisition and maintenance of JP behaviour more successfully than C-JP. Both treatment groups increased the use of JP methods after only four OT sessions, however, more people improved in the experimental group within this time period and the data two months after the fourth session detected that their learning was more sustained, i.e. in contrast to the controls, they managed to keep JP adherence on the level achieved.

The PRISM-JP group also improved in pain and perception of self-efficacy. Perceived self-efficacy is seen by many as at least one important determinant of success arising from self-management interventions. Lorig et al. drew attention to the importance of self-efficacy as a mediator of better health outcomes in arthritis education, and as an explanation for the difficulty in directly linking education to change in health status (39).

The PRISM tasks apply a patient-centred approach and were used to identify individualised treatment goals and resources to support behaviour change. It is an interesting fact that PRISM-JP had no effect on the individual's perceived burden of disease, but on the patients' resources. This indicates that it is possible to activate individual resources without direct impact on the RA. It is reasonable to assume that it is an unrealistic aim to have a direct marked effect on ingrained perceptions of the impact of RA by means of time-limited occupational therapy, moreover when the aim is focused, as here, on JP education. However, attaching the JP education to aspects of the individual's life, where a perceivable change is possible, may be meaningful, even indispensible.

RA is a disease that requires a bio-psychosocial approach, i.e. effective biomedical based management as well as psycho-social considerations that promote an orientation on strength and resources and not on impairment and disability (40). Focusing on resources, as the PRISM+ task did, had remarkable and powerful effects in a short timeframe. Successful resource activation may be explained by several facts. Firstly, it is a well-known fact in learning psychology, that focusing on resources and striving for attractive goals increases motivation (41), possibly by activating different neurotransmitter-systems and cerebral regions (42). Secondly, the patients were in the position of experts when talking about their resource, mainly favourite leisure activities (genealogy, motorbike riding, reading literature, grandchildren) which shifted the relationship between health professional/expert and patient/layperson to a balanced encounter between two equals. We assume that patients perceived these changes and were more open to learn JP 'from the OT expert' when having had the possibility to demonstrate own capacities and strengths.

Recruitment for this study was difficult. Besides language and travel barriers, the importance and potential of JP education may be questioned by some rheumatologists

and patients, as a consequence of efficient biologic drug therapy. Importantly however, the PRISM assessment disclosed needs in many aspects of life, even in well-controlled patients. Thus there remains a need to support coping and self-management abilities.

Occupational therapy interventions, such as JP education, may well offer this to their clients provided that interventions are individually tailored (17) and a psycho-educational approach is adopted (4, 7, 8). After only a 2-day training, OTs were well prepared to provide this more powerful intervention within only four sessions, which corresponds to average time usually spent on conventional JP education in Switzerland. During the supervision sessions the OTs providing the PRISM-JP education reported that the use of PRISM enhanced patient-therapist communication and enriched the therapeutic process.

There are some limitations to this study: sample size and follow-up time do not allow conclusions about functional improvements, such as hand status. Secondly, although the D-JPBA-S assesses common everyday tasks, we do not know if patients generalised their JP behaviour. Thirdly, the participants were not restricted to either early or late RA. It is likely that, in the course of the disease, there is an ideal phase for functional improvements through JP interventions. New studies indicate that an educational-behavioural JP intervention in early RA maintains long-term functional ability (7, 8), but in our experience, patients usually are not referred to occupational therapy as long as there are no functional limitations.

Conclusions

This study demonstrated that individual JP education improved JP behaviour regardless from the teaching strategy. However, individualised, resource-activating JP education can increase behavioural and psychological benefits. In many countries JP education is provided in group settings, probably because of treating larger numbers of patients at lower costs and at the same time taking advantage of group interaction and peer-role modeling. Therefore, future studies in patient education should apply focused resource activation and assess its effects of on motivational processes and outcomes also in group settings.

Practice implications

PRISM-JP more effectively supported learning of JP methods, with meaningful occupations, resource activation and self-efficacy acting as important mediators. PRISM improved patient-clinician communication and is feasible for occupational therapy.

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References

1. Backman C, Fairleigh A, Kuchta G. Occupational Therapy. In: St. Clair E, Pisetsky D, Haynes B, editors. Rheumatoid Arthritis. 1st ed. Philadelphia: Lippincott Williams & Wilkins; 2004. p. 431-9.
2. Heiberg T, Finset A, Uhlig T, Kvien TK. Seven year changes in health status and priorities for improvement of health in patients with rheumatoid arthritis. Ann Rheum Dis. 2005;64(2):191-5.
3. Hammell KW. Dimensions of meaning in the occupations of daily life. Can J Occup Ther. 2004;71(5):296-305.
4. Hammond A, Lincoln N, Sutcliff L. A crossover trial evaluating an educational-behavioural joint protection programme for people with rheumatoid arthritis. Patient Educ Couns. 1999;40:1044-51.
5. Hammond A, Lincoln N. The effect of a joint protection education programme for people with rheumatoid arthritis. Clin Rehabil. 1999;13:392-400.
6. Taal E, Rasker J, Wiegman O. Patient education and self-management in the rheumatic diseases: a self-efficacy approach. Arthritis Care Res. 1996;9:229-38.
7. Hammond A, Freeman K. One-year outcomes of a randomized controlled trial of an educational-behavioural joint protection programme for people with rheumatoid arthritis. Rheumatology (Oxdford). 2001;40:1044-51.
8. Hammond A, Freeman K. The long-term outcomes from a randomized controlled trial of an educational-behavioural joint protection programme for people with rheumatoid arthritis. Clin Rehabil. 2004;18:520-8.
9. Newman S. What is meant by self-management and how can its efficacy be established? Rheumatology (Oxford, England). 2001;40(1):1-4.
10. Carver C, Scheier M. Vigilant and avoidant coping in two patient samples. Attention and avoidance strategies in coping with aversiveness. Seattle WA: Hogrefe & Huber; 1993. p. 295-320.
11. Cassell E. The nature of suffering. N Engl J Med. 1982;306:639-45.
12. Buchi S, Buddeberg C, Klaghofer R, Russi E, Brandli O, Schlosser C, et al. Preliminary validation of PRISM (Pictorial Representation of Illness and Self Measure) - a brief method to assess suffering. Psychotherapy & Psychosomatics. 2002;71:333-41.
13. Buchi S, Sensky T, Sharpe L, Timberlake N. Graphic representation of illness: a novel method of measuring patients' perceptions of the impact of illness. Psychotherapy & Psychosomatics. 1998;67(4-5):222-25.
14. Kassardjian CD, Gardner-Nix J, Dupak K, Barbati J, Lam-McCullock J. Validating PRISM (Pictorial Representation of Illness and Self Measure) as a measure of suffering in chronic non-cancer pain patients. J Pain. 2008;9(12):1135-43.
15. Buchi S, Sensky T. PRISM: Pictorial Representation of Illness and Self Measure. A brief nonverbal measure of illness impact and therapeutic aid in psychosomatic medicine. Psychosomatics. 1999;40(4):314-20.
16. Hobfoll SE. Conservation of resources. A new attempt at conceptualizing stress. Am Psychol. 1989;44(3):513-24.

17. Richman W. examining the effects of post-training interventions on transfer of training [dissertation Sciences and Engineering]; 1999.
18. Arnett F, Edworthy S, Bloch D, McShane D, Fries J, Cooper N. The American Rheumatism Association 1987 revised criteria for the classification of rheumatoid arthritis. Arthritis Rheum. 1988;31:315-24.
19. Hochberg M, Chang R, Dwosh I, Lindsey S, Pincus T, Wolfe F. The American College of Rheumatology 1991 revised criteria for the classification of global functional status in rheumatoid arthritis. Arthritis Rheum. 1992;35:498-502.
20. Altman DG. Practical statistics for medical research. London: Chapman&Hall; 1991. p. 87-8.
21. Cordery J, Rocchi M. Joint Protection and Fatigue Management. Rheumatologic Rehabilitation: Assessment and Management. Bethesda: The American Occupational Therapy Association, Inc; 1998. p. 279-322.
22. Bandura A. Self-efficacy: towards a unifying theory of behaviour change. Psychol Rev. 1977;84:191-215.
23. Bandura A. Self-regulation of motivation through anticipatory and self-reactive mechanisms. Nebraska Symposium on Motivation. 1990;38:69-164.
24. Kanfer F, Gaelick L. Self-managment methods. helping people change: a textbook of methods. 3rd ed. New York: Pergamon Press; 1989.
25. Niedermann K, Forster A, Hammond A, Uebelhart D, de Bie R. Development and validation of a German version of the joint protection behavior assessment in patients with rheumatoid arthritis. Arthritis Rheum. 2007;57(2):249-55.
26. Mueller A, Hartmann M, Mueller K, Eich W. Validation of the arthritis self-efficacy short-form scale in German fibromyalgia patients. Europ J Pain. 2002;7(2):163-71.
27. Niedermann K, Forster A, Ciurea A, Hammond A, Uebelhart D, de Bie R. Development and Psychometric Properties of a Joint Protection Self-Efficacy Scale (JP-SES) using Rasch Analysis (submitted). 2008.
28. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. Acta Psychiatr Scand. 1983;67(6):361-70.
29. Pincus T, Griffith J, Pearce S, Isenberg D. Prevalence of self-reported depression in patients with rheumatoid arthritis. Br J Rheumatol. 1996;35(9):879-83.
30. Jones E, Hanly J, Mooney R, Rand L, Spurway P, Eastwood B. Strength and function in the normal and rheumatoid hand. J Rheumatol. 1991;18:1313-8.
31. Prevoo M, van 't Hof M, Kuper H, van Leeuwen M, van de Putte L, van Riel P. Modified disease activity scores that include twenty-eight-joint counts. Development and validation in a prospective longitudinal study of patients with rheumatoid arthritis. Arthritis Rheum. 1995;38:44-8.
32. Schmidt S, Mühlan H, Power M. The EUROHIS-QOL 8-item index: psychometric results of a cross-cultural field study. Eur J Public Health. 2005;16(4):420-8.
33. Spiegel T, Spiegel J, Paulus H. The joint alignment and motion scale: a simple measure of joint deformity in patients with rheumatoid arthritis. J Rheumatol. 1987;14:887-92.
34. Brühlmann P, Stucki G, Michel B. Evaluation of a German version of the physical dimension of the Health Assessment Questionnaire in patients with rheumatoid arthritis. J Rheumatol. 1994;21:1245-9.
35. Fransen J, Langenegger T, Michel B, Stucki G. Feasibility and validity of the RADAI, a self-administered rheumatoid arthritis disease activity index. J Rheumatol. 2000;39:321-27.
36. Antonovsky A. The structure and properties of the sense of coherence scale. Soc Sci Med. 1993;36(6):725-33.
37. Pocock J. Clinical Trials: A Practical Approach. Chichester: John Wiley and Sons; 1983. p. 129/30.
38. Wright BD. Rack and Stack: Time 1 vs. Time 2. . Rasch Measurement Transactions. 2003;17(1):905-6.
39. Lorig K, Chastain RL, Ung E, Shoor S, Holman HR. Development and evaluation of a scale to measure perceived self-efficacy in people with arthritis. Arthritis Rheum. 1989;32(1):37-44.

40. McSherry WC, Holm JE. Sense of coherence: its effects on psychological and physiological processes prior to, during, and after a stressful situation. J Clin Psychol. 1994;50(4):476-87.
41. Elliot AJ, Sheldon KM. Avoidance achievement motivation: a personal goals analysis. J Pers Soc Psychol 1997;73:171-85.
42. Hollerman JR, Tremblay L, Schultz W. Involvement of basal ganglia and orbitofrontal cortex in goal-directed behavior. Prog Brain Res. 2000;126:193-215.

Chapter 8

6 and 12 months' effects of individual joint protection education in people with rheumatoid arthritis. A randomized controlled trial

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Abstract

Background: Group joint protection (JP) education in people with rheumatoid arthritis (RA) using psycho-educational teaching strategies is more effective than JP education using conventional teaching methods. It is unclear if this applies also for an individual approach. The Pictorial Representation of Illness and Self Measure (PRISM) was used to identify a) individual JP education goals; b) an individually relevant life aspect. The objective of this study was to compare the effects of individual PRISM-based JP education (PRISM-JP) with conventional JP education (C-JP) in people with RA.

Methods: An assessor-blinded randomized controlled trial was conducted in 4 rheumatology centers. Patients were randomized to PRISM-JP or C-JP, consisting of 5 JP education sessions over 3 months. Primary outcome was JP behaviour at 6 and 12 months.

Results: A total of 53 RA patients participated. At 6 and 12 months, C-JP (n=27) and PRISM-JP (n=26) improved their JP behaviour ($p<0.000$), the PRISM-JP group did significantly better at 6 months ($p>=0.018$) and 12 months ($p=0.038$). JP self-efficacy (JP-SES) was improved in both groups at 6 months ($p=0.03$). Within group analysis at 12 months showed that the PRISM-JP group had better JP self-efficacy ($p=0.02$) and grip strength ($p=0.04$) and perceived less disease activity ($p=0.05$).

Conclusion: In contrast to group JP education, a one-on-one setting improved JP behaviour significantly regardless of the teaching strategy. The more pronounced use of JP methods in the PRISM group was associated with increased grip strength, JP self-efficacy and less perceived disease activity.

Introduction

There is evidence that psycho-educational group joint protection (JP) interventions for people with rheumatoid arthritis (RA) are effective on JP adherence and hand functional abilities in the short- and long-term [1-3]. These results support the importance of occupational therapy and hand JP education in the management of people with RA. In Switzerland JP education is usually provided in a one-on-one approach. It is currently unclear, whether the effects of psycho-educational JP education in group settings are applicable to an individual approach. Furthermore, despite the fact that JP research consistently has demonstrated the superiority of psycho-educational teaching strategies, the implementation of this approach requires special attention [4] . Also in Switzerland, occupational therapists predominantly apply an educational approach in JP education, providing knowledge and skills by use of conventional teaching methods. Conventional teaching methods include giving information, demonstrations and supervised practice of JP methods.

The challenge in JP education is not only to achieve short-time learning effects, but moreover behavioural changes and long-term adherence. However, conventional teaching strategies usually do not achieve these aims [5,6]. Adherence, i.e. performing a behaviour sufficiently and long enough to be effective, may determine the outcome of an intervention. Several reasons were identified for not adhering to JP: perception of not being capable of implementing JP behaviour, lack of motivation, not perceiving benefit of adhering, insufficient or inconsistent advice from health professionals and lack of time [7].

The Pictorial Representation of Illness and Self Measure (PRISM) was used to guide an individual approach in JP education [8]. PRISM is a brief interactive hands-on tool, requiring simple instructions and little time. The standard PRISM task was developed to quantitatively and qualitatively assess a person's suffering caused by an illness and/or pain [9,10]. This perceived impact of disease is related to restrictions or losses in aspects of life that are most salient for that person. An extension of the tool (PRISM+ task) visually summarizes relationships between illness and other important aspects of the patient's life (e.g. work, family, hobbies, friends). In routine [11] as well as specialized [12] clinical care for patients with physical illness PRISM has demonstrated high therapeutic potential in reinforcing client-centered approach.

In this study we tested the hypothesis that individual, PRISM-facilitated and resource-oriented JP education (PRISM-JP) in RA patients would improve JP behaviour and adherence compared to conventional JP education (C-JP) up to twelve months after the JP-intervention. We assumed that that the client-centred approach applied by PRISM, with focus on meaningful tasks and attractive goals would enhance patients' motivation for collaboration and be an efficient way of improving transfer of JP education to daily life [13].

At 3-months follow-up both groups improved in JP behaviour, the PRISM-JP group additionally improved in pain scores, arthritis self-efficacy and JP self-efficacy. This

publication reports on JP behaviour and other outcomes at the 6 and 12 months follow-up.

Methods

Design and randomisation

A multicenter randomized controlled trial was conducted, according to the extended CONSORT statement to randomized trials of non-pharmacologic treatment [14].

Randomisation was stratified for each centre and a four-block sequence [15] was performed to ensure balanced allocation to the two groups. Patients were randomly assigned to C-JP or PRISM-JP using sequentially numbered, concealed treatment allocations prepared in advance. Blinding of treating occupational therapists (OTs) and patients was not feasible, but the assessor rating the primary outcome (JP behaviour) was blinded.

Patients

Eligible Patients had to be: diagnosed with RA according to ACR guidelines [16]; in ACR functional class ll (limited in avocational activities), lll (limited in vocational and avocational activities) or IV (limited in usual self-care, vocational, and avocational activities) [17]; perceiving difficulties and/or pain in hands that justified occupational therapy, and sufficient German language skills. Severe deformities of finger, hand and shoulder joints were exclusion criteria, as for these patients more idiosyncratic JP methods have to be found. Patients were included between July 2006 and February 2008. They were asked to participate in a study aiming to evaluate two different educational approaches within occupational therapy, but they were not informed that the focus was on JP behaviour. Ethical approval was obtained in all regions involved and patients provided informed consent prior to participation. The study was registered in Clinical.Trials.gov.

Participating centres and care providers

Four convenience rheumatology centers, among them two university hospitals, one rheumatology-orthopaedic centre and one rheumatology rehabilitation clinic, in German-speaking regions of Switzerland participated. Two experienced rheumatology occupational therapists (OTs) in each centre provided the C-JP or the PRISM-JP. The expertise in providing JP education to people with RA required from the participating occupational therapists (OTs) ought to minimize bias of possible treatment effect estimates due to different experience in treating such patients [18]. The OTs providing the experimental JP (PRISM-JP) were trained by two researchers (SB, KN), an OT experienced in PRISM use and a research patient partner in a two-day course, and regular supervision meetings were held to ensure correct application of PRISM interventions during study. Furthermore, OTs were asked not to discuss treatment or participants

among each other. The interventions consisted of five 45-minutes sessions, four over a three weeks period and one booster session two months later.

The C-JP

The C-JP consisted of JP education previously matched over the four centers: oral and written information about RA and JP-principles [19]; demonstrations and supervised practice of hand JP methods, mostly in kitchen activities, and demonstration of appropriate assistive devices. 'Preparing instant coffee' was the assessed primary outcome activity and therefore not allowed as a practicing example [20]. OTs further documented any additional intervention in written form (e.g. home exercise, final provision of assistive devices, splints).

The PRISM-JP

The PRISM-JP consisted of the same JP education content, but based on the PRISM tasks (PRSIM standard and PRISM+) as well as the theories of social learning [21] and self-management [22] to individualize the JP education and to support motivation for using JP methods. When performing the standard PRISM task, the patient is shown a white A4-sized board with a fixed yellow disk (7cm in diameter) at the bottom right corner and is asked to imagine that the board represents his/her life as it currently is, and the disk represents his/her "Self". The person is then handed a red disk, 5 cm in diameter, representing his/her "Illness" and asked to place this illness disk where it reflects the perceived burden of illness in his/her life at present. The distance, in centimetres, between the centres of the "Illness" and the "Self" disks (range 0-27 cm) is the "Self-Illness Separation" (SIS). A smaller distance indicates higher impact of the disease, i.e. more suffering (Figure 1) [9].

Figure 1: Application of PRISM task and PRISM+ task

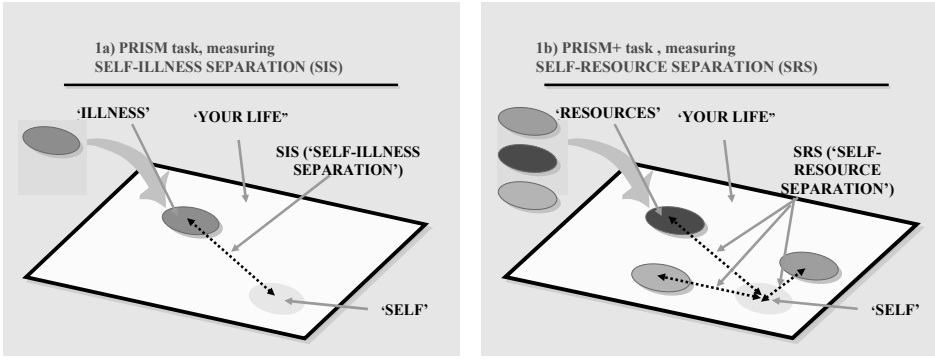


Fig. 1a) Self-Illness Separation (SIS) = measured distance between 'Self' and 'Illness' - a smaller SIS indicates a higher (negative) impact of the illness.
Fig. 1b) Self-Resource Separation (SRS) = measured distance between 'Self' and 'Resource'; a smaller SRS indicates a higher (positive) impact of the resource. In this example, the green resource (e.g. representing family/friends) is perceived as the resource with the highest positive impact, the blue resource (e.g. representing work) is perceived as the resource with the lowest positive impact.

When performing the PRISM+ task, further disks, similar to the illness disk but of different colours, represent important aspects of the patient's life (e.g. leisure activities or social activities), summarizing relationships between the illness and other aspects of the patient's life in visual form [11]. The "Self-Resource Separation" (SRS; range 0-27 cm) is used accordingly but its interpretation is different from the SIS: a larger distance indicates a less positive impact (of life aspects), thus possibly a resource/life aspect that should get more attention. By this, a smaller SRS would indicate a more positive impact.

The contents of the PRISM-JP interventions were allocated to the sessions 1 to 5 and summarised in a short manual to guide the interventions. The contents of the C-JP were not allocated to specific sessions.

In session 1, the standard PRISM task was used to identify tasks where performance was difficult due to RA. After placing the illness disk SIS was measured and the patient was asked to describe in which activities and why problems occurred. JP education and JP practice were linked with these individually relevant tasks.

In *session 2,* The PRISM+ task helped find an individual resource to care for during the therapy process. After putting their resource disks (for study purposes previously framed as: 1) personal care, 2) work, 3) family/friends, 4) leisure activities) the patient was asked which resource (s)he considered the most important to pay attention to during the therapy process. SRS was measured. The resource was not to be related to illness related problems and JP activities but to perceived positive activities, e.g. listening music, going to cinema, activities with friends and family. The idea was to support motivation for JP behaviour by additional focus on a life aspect that represented positive memories for the patient.

In *sessions 3 and 4*, the selected resource was evaluated and reinforced.

In *session 5, after the 3-months follow-up assessment,* the 2-month in-between period was evaluated by applying the PRISM tasks and, based on this, JP methods and key messages were repeated, including the patient's choice of activity, reinforcement of successful application and problem-solving for perceived barriers.

JP education and practice were part of every session. They became progressively complex, starting with self-monitoring of hand use and activities causing pain and difficulties; proceeding onto selecting one or several JP principle(s) to applying (referring to life areas defined in session 1) and practicing JP methods within individually selected complex activities and discussing and applying transfer of JP methods to other activities. Energy conservation was addressed in sessions 4 and 5.

Homework tasks consisted of reading booklets about RA and JP methods, edited by the Swiss League Against Rheumatism, practicing selected JP methods and the same complex JP activity, applying selected JP principles to various situations in short- and mid-term (between session 4 and follow-up assessment). Mutual g*oal agreement on homework tasks and self-monitoring* were important integral parts. Homework was evaluated at the beginning of the subsequent session, where facilitators, barriers and possible solutions were discussed. In session 5, patients were asked to define mid and long-term goals, i.e. at 6 and 12 months, with the idea of supporting adherence by directing the attention on a longer-term perspective.

Social support: Participants were encouraged to discuss the reading material with their partners and invite them to participate in sessions 4 and 5.

Outcomes and outcome measures

Comprehensive assessments at baseline (T0) and 6 (T1) and 12-months (T2) follow-ups were administered.

Primary outcome measure

Joint protection behaviour: was assessed using the German version of the Joint Protection Behavioural Assessment D-JPBA-S [20], by videotaping nine tasks required for the activity 'preparing instant coffee' (e.g. turning tap, carrying pan, opening coffee jar). Video recordings were transferred to Pinnacle Instant CD/DVD 11.0 software (Pinnacle systems, Mountain View, CA) and edited in a mixed sequence on compact discs for assessment. One experienced rheumatology OT, blinded to the patients' treatment allocation and time point of recording, rated the use of JP methods in all tasks as correct, partially correct or incorrect, following the instructions of the manual.

Secondary outcome measures

Hand function: Grip strength for the dominant hand was measured using a Jamar hand dynamometer [23]. Hand pain was assessed with a 0-10 VAS scale.

A set of questionnaires, all validated in the German language was used.

Functional assessment and quality of life

- Health Assessment Questionnaire (HAQ), a disease specific self-administered 20-item questionnaire, including rating of general health [24]
- Rheumatoid Arthritis Disease Activity Index (RADAI) to assess s*elf-perceived* disease activity and typical RA symptoms such as pain and morning stiffness [25].
- EUROHIS-QUOL 8, an 8-item WHO quality of life questionnaire assessing general quality of life [26]

Psychological status

- Arthritis self-efficacy scale, German Version (A-SES-D), an 8-item self-administered questionnaire [27]
- Hospital Anxiety and depression Scale, German Version, HADS-D [28]
- JP-specific self-efficacy, a 10-item scale assessing perceived ability to perform JP across a variety of situations [29].
- *Sense of Coherence (SOC),* a 13-item self-administered questionnaire measuring the dimensions comprehensibility, manageability and meaningfulness regarded as stable person-related characteristics [30], therefore measured at baseline and 12-months follow-up.

Other data assessed

Patients' and disease characteristics were measured at baseline*. Drug treatment* was assessed at baseline and 12 months follow-up. Due to the short trial duration hand status and disease activity were assessed only at T0 and T2, as they were not expected to change in short-term or due to JP use.

Hand status

- Range of motion (ROM) for active wrist and finger joint motion were assessed for the dominant hand using a goniometer.
- Finger and wrist joint deformity of dominant hand was assessed using the Joint Alignment and Motion Scale (JAM) [31]

Indicators for disease activity

- *Disease activity:* using the Disease Activity Score (DAS28), calculated from the results of a 28 tender joint count, a 28 swollen joint count and erythrocyte sedimentation rate [32]
- Self-perceived disease activity was measured using the Rheumatoid Arthritis Disease Activity Index (RADAI), a 5-item questionnaire assessing self-perceived disease activity and typical RA symptoms such as pain and morning stiffness [33]

PRISM-data (PRISM-JP group only)

Self-Illness Separation SIS, derived from the standard PRISM task (perceived burden of illness) and the PRISM+ task (resource activation) were assessed for the intervention group.

Statistics

Sample size calculations [34] were based on data from the D-JPBA-S validation study [20]. A minimum of 22 participants in each group was needed to detect a 20% difference in joint protection behaviour scores, assuming a mean change of 5.5 points (SD 3.7) on a linear scale, power of 90% and significance level of 0.05. A 20% drop out rate was added and to reach the same even number over the 4 centers, inclusion of 56 patients was necessary.

Rasch analysis was performed on the D-JPBA-S and JP-SES data to convert the ordinal raw data to interval scaled data [20,35]. For each questionnaire, the data of the different time points were transformed within the same frame of reference [36].

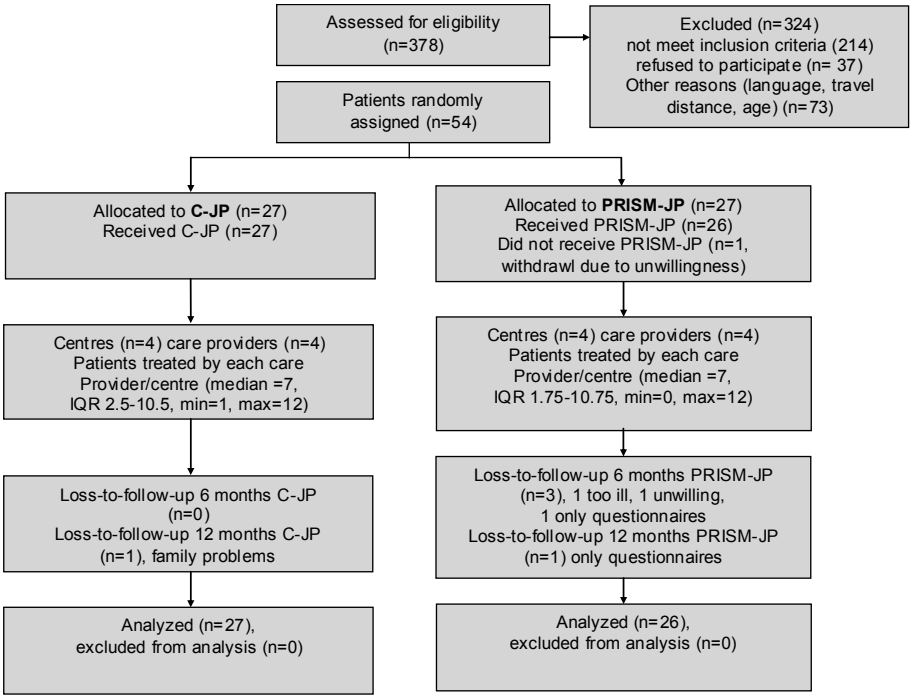
Intention to treat analysis was performed. Missing values at 6 months were imputed with the values of 12 months (where available); missing values at 12 months were imputed with the baseline values.

To analyse the between-group differences of the JP interventions on JP behaviour, self-efficacy and health status after 6 and 12 months, the changes from baseline (follow-up minus baseline values) were compared by analysis of variance (ANOVA). They are presented as a mean difference in change between the groups. Paired t-tests were applied for within group comparisons at 12 months where appropriate.

Results

Flow of participants through study is presented in Figure 2: the number of eligible patients is a retrospective estimation, as it was not feasible to establish a systematic reporting of eligible patients in all involved centers. Recruiting all patients took approximately 1.5 years. Distribution of treated patients was unequal over the 4 centers (14 / 15 / 24 / 1 patients), but equally distributed between C-JP and PRISM-JP within the centers. The rheumatology rehabilitation clinic recruited only one patient over 8 months and stopped participation when the OT trained for providing the PRISM-JP changed job.

Figure 2: Flow of participants through study



The participants of the two groups were well matched in relation to demographic and clinical data (Table 1). The average age and disease duration of the experimental patients were higher and consequently the average professional work frequency was lower compared to the controls.

Table 1: Demographic and clinical baseline variables of study participants (n=53)

	Conventional JP education (n= 27)	**PRISM-based JP education (n=26)**
Gender (m/f)	5, 22	4, 22
Age, years	53.44 (15.71)	62.08 (12.61)
Disease duration, years	8.30 (9.75)	10.23 (7.64)
Patients < 65 years / with work ability	22 / 14 (64%)	17 / 10 (59%)
Weekly working hours	31.5 (12.31)	22 (14.22)
Patients with former OT / years since	4 / 5.75 (5.74)	6 / 8.17 (4.62)
Rheumatoid nodules (%)	3 (11%)	2 (8%)
Rheumatoid factor (%)	18 (66%)	20 (77%)
ANA (%)	15 (56%)	16 (62%)
Erosions (%)	15 (56%)	18 (69%)
ACR functional class	2 (1-4)	2 (1-4)
Biologicals (anti-TNF, Rituximab)	8 (30%)	9 (33%)
DMARDs (no. of patients and %)	22 (82%)	20 (77%)
Steroids (no. of patients)	11 (41%)	13 (50%)
NSAIDs (no. of patients)	9 (33%)	11 (42%)
Analgetics	7 (26%)	2 (8%)

Values are the mean (SD), unless stated otherwise; NA = not available
ANA = anti-nuclear antibodies, DMARDs = disease-modifying anti-rheumatic drugs; NSAIDs = non-steroidal anti-inflammatory drugs.

Adherence to treatment and follow-up. One patient (PRISM-JP) did not attend all JP sessions (2 out of 4) and the follow-up sessions, because travelling was too stressful; but she did fill out all questionnaires. Two other patients of the PRISM-JP group did not attend the follow-up assessments at 6 months, but both accepted to participate at the 12-months follow-up. At the 12 months follow-up one patient from the C-JP group was unable to participate.

Additional treatment. Eight patients received additional OT after the intervention period, three in the PRISM-JP group and five in the C-JP group. Two patients received work place adaptation and counselling, two had static splints for night use, one finger splints; three patients (2 C-JP, 1 PRISM JP) underwent hand surgery (wrist arthrodesis), shortly after the 6-months follow-up.

Paired samples t-tests were applied for calculating change from baseline to follow-up at 6 and 12 months

6 months follow-up

Joint protection behaviour increased significantly in both groups from baseline to 6 months follow-up. Improvement within the PRISM-JP group was significantly larger (p=0.018) (Table 2). In the PRISM-JP group 73% (17 patients) increased JP behaviour scores by 20% and 53% (14 patients) by more than 30% (>5.4 points, which corresponds to smallest detectable difference SDD [20], whereas in the C-JP group 22% (6 patients) increased by 20% and 19% (5 patients) by more than 30%.

JP-self-efficacy was significantly increased in both groups. No further differences between or within the groups on any variables were present.

12-months follow-up

At 12 months follow-up, both groups showed more use of JP methods ($p<0.001$) compared to baseline, with significantly better JP adherence in the PRISM group ($p=0.038$) (Table 3). Again considerably more PRISM-JP participants had increased by 20% and by more than 30% compared to baseline: 16 patients and 14 patients respectively, compared to 10 and 5 patients respectively in the C-JP group.

Within group analysis showed improved JP specific self-efficacy ($p=0.02$) and improved grip strength ($p=0.04$) in the PRISM-JP group, whereas the C-JP group had improved depression scores (HADS-D), quality of life scores (EUROHIS-QUOL 8) and disease activity (DAS28). The quality of life scores were significantly different between the PRISM-JP and the C-JP groups (Table 2).

Drug treatment. In both groups, the initial rate of patients on biologicals (anti-TNF and Rituximab) disease-modifying anti-rheumatic drugs (DMARDs), non steroidal anti-inflammatory drugs (NSAIDs), glucocorticoids and analgetics was similar. About one third of the patients in both groups received combination therapy of biologicals and DMARDs initially and after one year (Table 3).

Subanalysis of PRISM-JP group

No change in PRISM-measured perceived burden of disease and resource activation occurred at 6 and 12 months (Table 4).

Table 2. Primary and secondary outcome variables: at baseline and mean changes (standard deviation SD) at 6 and 12 months follow-up

	Conventional joint protection education			PRISM-based joint protection education			Δ between groups 6 months	Δ between groups 12 months
	Baseline (n=27)	6 months change (n=27)	12 months change (n=27)	Baseline n=26	6 months change (n=26)	12 months Change (n=26)	p-value	p-value
D-JPBA-S	4.01 (3.89)	3.0 (3.4) ***[b)]	2.8 (3.1) ***[b)]	3.78 (4.59)	5.4 (3.8) ***[b)]	4.8 (3.8) ***[b)]	0.02*[a)]	0.04*[a)]
ASES-D	7.12 (1.56)	-0.4 (1.8)	-0.5 (1.6)	6.51 (2.07)	0.1 (2.0)	-0.1 (1.9)	0.31	0.38
JP-SES	16.24 (6.10)	3.1 (4.6) **[b)]	1.9 (5.2)	16.59 (5.21)	2.5 (5.7) *[b)]	3.3 (6.9) *[b)]	0.70	0.39
HADS-A	4.33 (2.92)	-0.1 (2.7)	0.0 (2.2)	6.92 (4.33)	-0.4 (3.0)	-0.1 (2.9)	0.73	0.89
HADS-D	4.33 (3.16)	-0.3 (2.9)	-0.8 (2.2) *[b)]	5.27 (3.32)	-0.3 (2.4)	0.5 (3.0)	0.97	0.09
Hand pain	2.89 (2.98)	0.44 (2.22)	-0.44 (2.34)	3.08 (3.06)	-0.15 (2.68)	-0.28 (2.62)	0.38	0.82
Grip strength	15.50 (9.46)	1.3 (4.3)	0.2 (6.0)	14.88 (9.36)	2.0 (6.0)	2.9 (6.8) *[b)]	0.62	0.13
HAQ	1.08 (0.69)	1.2 (0.9)	1.0 (0.6)	1.18 (0.61)	1.1 (0.6)	1.1 (0.6)	0.22	0.96
EUROHIS-QOL-8	2.71 (0.67)	0.05 (0.53)	0.18 (0.42) *[b)]	2.61 (0.49)	0.06 (0.51)	-0.09 (0.50)	0.94	0.04*[a)]
SOC	5.31 (0.86)	NA	0.12 (0.35)	4.91 (1.08)	NA	0.17 (0.46)	0.24	
DAS28	3.72 (1.67)	NA	-0.67 (1.60) *[b)]	3.70 (1.67)	NA	-0.33 (1.23)	NA	0.39
RADAI	3.23 (2.18)	NA	-0.58 (1.56)	3.95 (2.41)	NA	-0.78 (1.87) *[b)]	NA	0.68
Arthritis pain	3.30 (2.91)	NA	-0.2 (2.2)	3.92 (3.12)	NA	-0.5 (2.3)	NA	0.70
ROM wrist FLEX#	56.67 (17.38)	NA	-1.11 (11.12)	54.04 (21.96)	NA	0.19 (14.03)	NA	0.71
ROM wrist EXT#	48.52 (19.21)	NA	-3.70 (9.96)	45.19 (24.72)	NA	-3.27 (10.86)		0.88
ROM MCP FLEX#	78.70 (7.92)	NA	2.78 (7.76)	78.65 (11.54) 0.19	NA	0.58 (5.35)	NA	0.24
ROM MCP EXT #	2.41 (6.70)		-2.04 (6.39)	(6.08)		-0.58 (5.71)		0.39
JAM wrist #	1.96 (0.98)	NA	0.19 (0.62)	2.19 (1.13)	NA	0.39 (0.72)	NA	0.43
JAM MCP #	0.96 (0.65)	NA	-0.07 (0.78)	2.23 (1.21)	NA	0.39 (0.66)	NA	0.58

D-JPBA-S = JP Behavioural Assessment; JP-SES = JP Self-Efficacy Scale; ASES-D = Arthritis Self-Efficacy Scale; HADS = Hospital Anxiety and Depressions Scale (-D = Depression; -A = Anxiety subscale) hand pain and grip strength (in kg), # of dominant hand; HAQ = Health Assessment Questionnaire; EUROHIS-QOL-8 = Quality of Life 8 Item Index; SOC = Sense of Coherence; DAS28 = Disease Activity Score in 28 joints; RADAI = Rheumatoid Arthritis Disease Activity Index; ROM = Range of Motion; JAM = Joint Alignment and Motion Scale;
Between-group analysis: *[a)] $p \leq 0.05$; **[a)] $p \leq 0.01$; ***[a)] $p < 0.001$
Within-group analysis: *[b)] $p \leq 0.05$; **[b)] $p \leq 0.01$; ***[b)] $p < 0.001$ (all compared to baseline)
ANOVA was applied for calculating between group changes from baseline to follow-up for all variables
Paired samples t-tests for calculating within group change from baseline to follow-up for all variables

Table 3. Drug therapy at baseline and 12 months follow-up

	Conventional joint protection education (C-JP)		PRISM-based joint protection education (PRISM-JP)	
	Baseline n=27	12 months n=27	Baseline n=26	12 months n=26
Biologicals (anti-TNF, Rituximab)	8 (30%)	9 (33%)	9 (33%)	11 (41%)
DMARDs (no. of patients and %)	22 (82%)	21 (78%)	20 (77%)	22 (82%)
Steroids (no. of patients)	11 (41%)	10 (37%)	13 (50%)	11 (41%)
NSAIDs (no. of patients)	9 (33%)	6 (22%)	11 (42%)	9 (33%)
Analgetics	7 (26%)	2 (7%)	2 (8%)	2 (8%)

DMARDs = disease-modifying anti-rheumatic drugs; NSAIDs = non-steroidal anti-inflammatory drugs

Table 4: PRISM measured burden of disease and resource activation (Intervention group)

PRISM measure	Baseline	6 months	12 months	Within group p-value (6 months)	Within group p-value (12 months)
Standard PRISM task ($SIS_{Problem}$)	12.60 (8.5)	13.5 (7.5)	13.7 (7.1)	0.6	0.5
PRISM+ task ($SIS_{Resource}$)	10.0 (7.2)	8.0 (4.6)	8.1 (5.3)	0.1	0.2

SIS (Self - Illness Separation) = measured distance between 'Self' and 'Illness' (in standard PRISM task) and 'Self' and resource (in PRISM+ task)

$SIS_{Problem}$: an increasing SIS means less perceived burden of disease

$SIS_{Resource}$: a decreasing SIS means better resource activation

Discussion

The study showed that individual JP education increased JP behaviour at 6 and 12 months. Overall, PRISM-JP was more effective than C-JP. Continued adherence was high in the PRISM-JP group. At 12 months, the PRISM group showed increased JP-self efficacy and grip strength and decreased self-reported disease activity, which may be directly linked with continuously performing JP methods in a possibly sufficient amount. This confirmed previous evidence that a psycho-educational teaching approach is more successful than a conventional one, and confirmed our hypothesis that this may apply also in individual JP education.

Interestingly, average use of JP methods was also significantly increased in the C-JP group at 6 and 12 months. This is remarkable and different to what was observed in another JP study, where there were no effects on JP behaviour in the conventional JP education group at 12-months follow-up [3]. In contrast to that study, our participants had established RA and both interventions, PRISM-JP and C-JP, focused on JP behaviour and had the same duration. It may also be that a one-on-one approach has beneficial effects that outweigh the well-known advantages of group intervention i.e. group interaction and participants modeling [37].

However, although participants in both groups increased their JP behaviour significantly, only about 50% of the PRISM group and approximately 20% of the control group improved above the measurement error on the D-JPBA-S scale. Beyond the measure-

ment error there is the minimal clinically significant difference, which is the *'smallest difference in a score in a domain of interest that patients perceive as beneficial*' [38]. In JP behaviour, perceived benefits are less pain or better function; however, we do not know which improvements in JP use in which tasks reflect these benefits. In the PRISM-JP group, the JP education tasks were linked to individually meaningful and relevant activities and most often leisure activities were selected (38). By this, immediate benefit could be perceived which was considered a strong motivation. The C-JP used more 'purposeful' activities (kitchen household, self-care), but as in the PRISM-JP, and in contrast to comparable JP studies [1,3], the D-JPBA-S assessment activity, preparing instant coffee, was not allowed as practice example. Hammond stated that it was unknown to what degree patients were able to transfer the JP behaviour assessed by the JPBA to their individual daily activities [3]. In our study transfer from a practice activity to the assessment activity seemed to have happened in both treatment groups, but more successfully in the PRISM-JP group. This is in line with the increased JP self-efficacy in the PRISM group. In fact the increased JP specific self-efficacy at 6 and 12 months may indicate that PRISM-JP participants felt able to perform JP across a variety of situations.

Improved grip strength in the PRISM-JP group at 12 months follow-up was shown. Although JP behaviour is not considered to improve grip strength, but rather to facilitate tasks by working with less stress and effort, strength did improve [19]. Possibly the more regularly JP methods are applied, the easier and possibly with less pain tasks are performed. This may increase the amount of activity as well as strength. This is in accordance with findings in patients with early RA [3].

The C-JP group showed some improvements in disease activity, depression scores and quality of life. However, these changes are more probable related to positive drug treatment response than to a direct consequence of JP education, even more when considering the decreased JP adherence in this group between 6 and 12 months. Participants of the C-JP group were younger and had shorter disease duration and when they presented at a specialized rheumatology clinic in a stage of exacerbated disease activity, they were likely to be successfully treated with biologicals.

The study has its limitations. One was the recruiting of patients at two university hospitals and a specialized centre. It can be assumed that patients who are treated by early use of TNF and combination therapies are more present in such specialized clinics than in general rheumatology practices, and therefore not represent the typical general RA population. Moreover, these clinics represent high volume centres, this may indicate that the generalisibility of our findings depend on the OTs' experience and routine (39). Another limitation is that sample size was calculated for the primary outcome of JP behaviour, but not for functional ability, pain or physical and psychological health and thus study size prevented detection of further differences.

However, the PRISM intervention demonstrated to be appropriate for occupational therapy interventions, meeting important OT concepts. Meaningful occupations [39] to practice JP methods were identified by the PRISM standard task assessing life areas were burden of illness was perceived and by PRISM+ task identifying the resource to

support the therapy process. This ensured an individualized client-centered therapeutic approach. The aim of the PRISM intervention was to increase and support motivation and although there were no differences measured in the PRISM tasks, we assume that group differences may be explained by this approach. PRISM enhanced patient-therapist communication of individual aspects of illness, and enriched and improved the therapeutic process with salient information. After a two-day training OTs were able to perform the PRISM tasks and to take advantage on this approach. We suggest the use of PRISM in routine clinical practice, not restricted to RA or rheumatology patients.

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References

1. Hammond A, Lincoln N, Sutcliff L. A crossover trial evaluating an educational-behavioural joint protection programme for people with rheumatoid arthritis. Patient Educ Couns 1999;40:1044-51.
2. Hammond A, Freeman K. The long-term outcomes from a randomized controlled trial of an educational-behavioural joint protection programme for people with rheumatoid arthritis. Clin Rehabil 2004;18:520-8.
3. Hammond A, Freeman K. One-year outcomes of a randomized controlled trial of an educational-behavioural joint protection programme for people with rheumatoid arthritis. Rheumatology (Oxdford) 2001;40:1044-51.
4. Hammond A, Klompenhouwer PJ. Getting evidence into practice: implementing a behavioural joint protection education programme for people with rheumatoid arthritis Br J Occup Ther 2005;68(1):25-33.
5. Hammond A, Lincoln N. The effect of a joint protection education programme for people with rheumatoid arthritis. Clin Rehabil 1999;13:392-400.
6. Riemsma RP, Kirwan JR, Taal E, Rasker JJ. Patient education for adults with rheumatoid arthritis. Cochrane Database Syst Rev 2003(2):CD003688.
7. Taal E, Rasker JJ, Seydel ER, Wiegman O. Health status, adherence with health recommendations, self-efficacy and social support in patients with rheumatoid arthritis. Patient Educ Couns 1993;20(2-3):63-76.
8. Buchi S, Sensky T, Sharpe L, Timberlake N. Graphic representation of illness: a novel method of measuring patients' perceptions of the impact of illness. Psychother Psychosom 1998;67(4-5):222-5.

9. Buchi S, Buddeberg C, Klaghofer R, Russi E, Brandli O, Schlosser C, et al. Preliminary validation of PRISM (Pictorial Representation of Illness and Self Measure) - a brief method to assess suffering. Psychotherapy & Psychosomatics 2002;71:333-41.
10. Buchi S, Sensky T, Sharpe L, Timberlake N. Graphic representation of illness: a novel method of measuring patients' perceptions of the impact of illness. Psychotherapy & Psychosomatics 1998;67(4-5):222-25.
11. Buchi S, Sensky T. PRISM: Pictorial Representation of Illness and Self Measure. A brief nonverbal measure of illness impact and therapeutic aid in psychosomatic medicine. Psychosomatics 1999;40(4):314-20.
12. Kassardjian C, Gardner-Nix J, Dupak K, Barbati J, Lam-McCullock J. Validating PRISM (Pictorial Representation of Illness and Self Measure) as a measure of suffering in chronic non-cancer pain patients. J Pain 2008;9(12):1135-1143.
13. Richman W. examining the effects of post-training interventions on transfer of training [dissertation Sciences and Engineering]; 1999.
14. Boutron I, Moher D, Altman DG, Schulz KF, Ravaud P. Extending the CONSORT statement to randomized trials of nonpharmacologic treatment: explanation and elaboration. Ann Intern Med 2008;148(4):295-309.
15. Altman DG. Practical statistics for medical research. In. London: Chapman&Hall; 1991. p. 87-8.
16. Arnett F, Edworthy S, Bloch D, McShane D, Fries J, Cooper N. The American Rheumatism Association 1987 revised criteria for the classification of rheumatoid arthritis. Arthritis Rheum 1988;31:315-24.
17. Halm EA, Lee C, Chassin MR. Is volume related to outcome in health care? A systematic review and methodologic critique of the literature. Ann Intern Med 2002;137(6):511-20.
18. Cordery J, Rocchi M. Joint Protection and Fatigue Management. In: Rheumatologic Rehabilitation: Assessment and Management. Bethesda: The American Occupational Therapy Association, Inc; 1998. p. 279-322.
19. Niedermann K, Forster A, Hammond A, Uebelhart D, de Bie R. Development and validation of a German version of the joint protection behavior assessment in patients with rheumatoid arthritis. Arthritis Rheum 2007;57(2):249-55.
20. Bandura A. Self-efficacy: towards a unifying theory of behaviour change. Psychol Rev 1977;84:191-215.
21. Kanfer F, Gaelick L. Self-managment methods. In: helping people change: a textbook of methods. 3rd ed. New York: Pergamon Press; 1989.
22. Jones E HJ, Mooney R, Rand LL, Spurway PM, Eastwood BJ. Strength and function in the normal and rheumatoid hand. J Rheumatol 1991;18:1313-8.
23. Brühlmann P SG, Michel BA. Evaluation of a German version of the physical dimension of the Health Assessment Questionnaire in patients with rheumatoid arthritis. J Rheumatol 1994;21:1245-9.
24. Fransen J, Langenegger T, Michel B, Stucki G. Feasibility and validity of the RADAI, a self-administered rheumatoid arthritis disease activity index. J Rheumatol 2000;39:321-27.
25. Schmidt S, Mühlan H, Power M. The EUROHIS-QOL 8-item index: psychometric results of a cross-cultural field study. Eur J Public Health 2005;16(4):420-8.
26. Mueller A HM, Mueller K, Eich W. Validation of the arthritis self-efficacy short-form scale in German fibromyalgia patients. Europ J Pain 2002;7(2):163-71.
27. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. Acta Psychiatr Scand 1983;67(6):361-70.
28. Niedermann K, Forster A, Ciurea A, Hammond A, Uebelhart D, de Bie R. Development and Psychometric Properties of a Joint Protection Self-Efficacy Scale (JP-SES) using Rasch Analysis (submitted). 2008.
29. Antonovsky A. Personality and health: testing the sense of coherence model. In: Personality and disease. In: Personality and disease. New York: Wiley; 1990. p. 155-170.

30. Spiegel TM SJ, Paulus HE. The joint alignment and motion scale: a simple measure of joint deformity in patients with rheumatoid arthritis. J Rheumatol 1987;14:887-92.
31. Prevoo M, van 't Hof M, Kuper H, van Leeuwen M, van de Putte L, van Riel P. Modified disease activity scores that include twenty-eight-joint counts. Development and validation in a prospective longitudinal study of patients with rheumatoid arthritis. Arthritis Rheum 1995;38:44-48.
32. Fransen J LT, Michel BA, Stucki G. Feasibility and validity of the RADAI, a self-administered rheumatoid arthritis disease activity index. J Rheumatol 2000;39:321-27.
33. Pocock J. In: Clinical Trials: A Practical Approach. Chichester: John Wiley and Sons; 1983. p. 129/130.
34. Tennant A, Conaghan PG. The Rasch measurement model in rheumatology: What is it and why use it? When should it be applied, and what should one look for in a Rasch paper? Arthritis Rheum 2007;57(8):1358-62.
35. Wright BD. Rack and Stack: Time 1 vs. Time 2. Rasch Measurement Transactions 2003;17(1):905-6.
36. Taal E, Rasker JJ, Wiegman O. Group education for rheumatoid arthritis patients. Semin Arthritis Rheum 1997;26(6):805-16.
37. Jaeschke R, Singer J, Guyatt GH. Measurement of health status. Ascertaining the minimal clinically important difference. Control Clin Trials 1989;10(4):407-15.
38. Hammell KW. Dimensions of meaning in the occupations of daily life. Can J Occup Ther 2004;71(5):296-305.
39. Halm EA, Lee C, Chassin MR. Is volume related to outcome in health care? A systematic review and methodologic critique of the literature. Ann Intern Med 2002;137(6):511-20.

Chapter 9
General discussion

This thesis reports on research in various aspects of joint protection (JP) behaviour and behavioural change. The purpose of this research was to assess the effectiveness of patient education and more specifically, the effectiveness of individual JP education in people with rheumatoid arthritis (RA). The first step consisted of a systematic review of patient education in those with RA (chapter 2). The second step was the preparation of a randomised controlled trial (RCT), including a validation process of two outcome measures to be used in the RCT (chapters 3 and 4), and exploring determinants of JP behaviour (chapter 5). The final third step was performing the RCT to compare individual conventional JP (C-JP) education with JP education using the individualising PRISM (Pictorial Representation of Illness and Self Measure) (PRISM-JP). In chapter 6 this novel approach was illustrated with two cases, whereas chapters 7 and 8 reported on the short-term and long-term effectiveness of PRISM-JP.

In this final chapter, the main results and conclusions are critically reviewed and the impact of this research project on clinical practice of rheumatology occupational therapy and JP education for people with RA is discussed. Finally, suggestions for further research in this field are outlined.

Systematic review

Methodological considerations

A systematic review includes a comprehensive search strategy and a defined procedure to appraise and synthesize the available evidence from individual studies. We additionally rated the quality of the included study by means of the Amsterdam-Maastricht Consensus List for Quality Assessment (1) and the criteria set in the Cochrane Reviewers' Handbook for data extraction criteria (2). Together with the Cochrane review 'patient education for adults in rheumatoid arthritis' (3, 4) it was the first systematic review in the field of RA patient education which appraised the methodological quality of the included studies. Not surprisingly, both these systematic reviews found large differences between the included studies. The quality of a study, i.e. its internal validity and data extraction criteria reported, determines the validity of the results and generalisibility. However, systematic reviews judge the included studies based on the publications and thus it may be that missing quality issues were considered but not reported. In general, there was no correlation between later years of publication and quality improvement in the studies.

Methodological problems, such as unclear randomisation and intervention procedures, possible co-interventions, not reporting specified eligibility criteria or dropout rate or not performing an intention-to-treat analysis, may result in potential bias by overestimating or underestimating the demonstrated effects. This may thus mislead the authors in the interpretation of their results as well as prevent the readers from full transparency and understanding of the study. Both would be necessary to correctly transfer study findings into clinical practice (5). The main issues for internal validity as possible sources of bias in our review were 1) no description of withdrawal/drop out

rate and 2) patients not blinded to allocated intervention 3) no careful description of randomisation procedure and 4) no concealed treatment allocation. Blinding is a problem specific to care interventions (6). Patients usually are aware of which therapeutic intervention they are getting and moreover ethical requirements ask for providing the patients with full information (informed consent). Even more, careful description of steps ensuring internal validity, e.g. randomisation and treatment allocation would be of great value (7).

Findings, Comparisons with other reviews and implications

The gaps detected in our review were two-fold: 1) the gap between educational and psycho-educational interventions and 2) the gap between short-term and long-term effects. Our review concluded that programme targets were usually observed, i.e. knowledge improvement in educational programmes and behavioural outcomes, e.g. coping abilities, in psycho-educational programmes, but that only psycho-educational interventions had the potential to sustain these effects in the long-term. This was in agreement with the meta-analysis performed in the Cochrane review (3, 4), which detected, that only behavioural interventions had small short-term effects in functional ability and patients' global assessment, but none in the long-term. Recently an overview of systematic reviews (8) including four patient education reviews with minor or moderate limitations (4, 9-11) confirmed these findings.

Practical considerations

However, these systematic reviews were published between 2002 and 2004 and the studies included in the above mentioned systematic reviews were published between 1966 and 2002 (or 1987-1999 in our review). It may be questioned whether the interventions reported in these studies are still comparable to treatment protocols applied nowadays. If the current treatment protocols are different, then the generalisibility of the reported findings to current practice may be affected.

Nevertheless, educational interventions continue to be developed (12-15). In view of the clear wish of patients to receive written and verbal information about their condition, also the recently published NICE guidelines for the management of rheumatoid arthritis (16, 17) recommend *'offering verbal and written information to people with RA to improve their understanding of the condition and its management, and counter any misconceptions they may have'.* The guidelines also emphasize the need for further research to identify the most appropriate and effective educational methods, mainly to achieve benefits in the longer-term.

However, self-management programmes are now considered a fundamental aspect of care for all long-term conditions. Studies conducted after the systematic reviews' inclusion period confirmed that group education, led by healthcare professionals using a behavioural approach, was effective in this regard for people with RA (18-21). Consequently, the NICE guidelines recommend offering self-management programmes to

patients when appropriate. Also the development of our RCT experimental intervention was guided by the evidence that only psycho-educational interventions are able to change behaviour, support adherence and potentially achieve long-term effects.

The assessments (D-JPBA-S, JP-SES)

Methodological considerations

The psychometric properties of German (Deutsch) version of the Joint Protection Behaviour Assessment short form (D-JPBA-S) were assessed using Rasch analysis and traditional test theory (22). The application of Rasch analysis on the D-JPBA-S data was not only an innovative step for assessing content validity, but is in fact an essential requirement for the correct functioning of the scale.

When constructing a new scale, such as the Joint Protection Self-Efficacy Scale (JP-SES), fulfilling the requirements of fundamental measurements, being unidimensionality and scale additivity, are mandatory. Rasch analysis is considered state of the art for the development of new scales (22). For new scales procedures are applied more restrictive by selecting only items that are free of Differential Item Functioning (DIF), fit to model expectations and do not interfere with unidimensionality requirements, whereas for testing established scales, some leniency towards items may be accepted, for example when a clinically important item does not have perfect fit to the model or demonstrates DIF (22).

All these measurement issues are essential for outcome measures, for which valid change scores and parametric statistics are required. Valid change scores are very important when assessing changes over time, i.e. for people already in the upper ability range it is more difficult to achieve improvement, in contrast to people in the lower ability range. The same raw score change in the lower, middle or upper range of a scale has a different meaning, i.e. upper and lower tails demonstrate substantial raw score distortion. This nonlinearity is just what is being ignored by calculations based on raw score changes and may lead to harmful misinterpretations and obscure real changes (23). By transforming raw scores to linear data logit measures by Rasch analysis, the raw score differences in the upper tail may get much larger and the equal scale intervals help to interpret individual changes correctly.

Practical considerations for the D-JPBA-S

An important issue is the feasibility of the assessment for clinical use. The D-JPBA-S was mainly validated for use in research. The Rasch analysis highlighted that for valid change scores the ordinal raw data have to be converted into interval data (24). Theoretically the D-JPBA-S could be made available for daily practice by providing a score-to-measure conversion table that translates the ordinal (raw) scores to interval data, which would give a person location, i.e. information about the patient's ability (in this context in terms of JP behaviour). A conversion table, if provided, should be applied

with caution, as a minimum sample size is required to construct a conversion table. Rasch experts calculated *250 cases or 20 times the number of items, whichever is greater (*personal communication by A. Tennant, University of Leeds, UK) as basis for a trustworthy conversion table, which, moreover, could only be used for a population with the same characteristics.

Thus our recommendation for clinical practice is to use the D-JPBA-S as a screening instrument to observe an individual's JP behaviour, rather than an evaluation instrument.

Practical considerations for the JP-SES

The same reasons mentioned above (i.e. main purpose being for research, no conversion table available) preclude easy use in clinical practice of the JP-SES as well. The JP-SES can be used in clinical practice for assessing the patients' perceived ability of JP use in various situations at initial screening. The short- and long-term results of the RCT detected that JP self-efficacy is positively associated with increased use of JP-methods.

The RCT

Internal validity of the study

Randomized controlled trials (RCTs) provide the best evidence for the effectiveness of an intervention (25), but the methodology applied guides the reliability and credibility of its results. The extended CONSORT statement to Randomized Trials of Nonpharmacologic Treatment (7) summarizes the requirements for ensuring quality of RCTs in such trials. The authors stress the differences of non-pharmacological (care) interventions compared to pharmacological trials. Nonpharmacologic Trials usually test complex interventions involving several components. Such interventions are more difficult to describe, standardize, reproduce and administer consequently to all patients. However these variations may have an impact on the treatment effect, as well as may have the care providers' expertise and the centers' characteristics. There are some limitations that care interventions such as physio- or occupational treatments never can overcome due to the nature of such trials.

Nevertheless, it is crucial to design and carry out carefully the methodology steps that are possible. In the following we discuss the 'safeguards' implemented to ensure internal validity in this study. This helps to prevent from invalid conclusions because of bias.

Randomisation and concealment allocation

Random allocation was achieved by generating a random computer-generated series of numbers, performed by a senior researcher. Randomization was stratified for each

hospital and a four-block sequence was applied to ensure balanced allocation of participants to the two groups.

Correct treatment allocation is important as in RCTs where concealment allocation has not been utilized an overestimation of the treatment effect may occur. An increase of as large as 20 to 30% has been reported (26). The average bias associated with lack of adequate concealment allocation was more prevalent when outcomes were evaluated subjectively (pain, patient reported outcomes) than subjectively (death, ulcer closure).

Generally randomization and treatment allocation seemed to have worked in our RCT. The difference between the groups at baseline (mainly age and related variables) may thus be more due to chance than bias, and these differences are also associated with the small size of this study.

Blinding

In care studies blinding of participants, care providers and outcome assessors is difficult and except for the outcome assessor virtually impossible (6). Patients could not be blinded in our study, however, in the patient information sheet for this trial we presented both interventions as equally relevant and potentially effective. Additionally we did not disclose to the patients that the study was about JP education. We assumed that patients could link specific expectations to JP or might be reluctant to undergo JP education and may be more motivated to participate in a study 'evaluating the effects of two individualized educational approaches in occupational therapy'. Patients were also kept blinded about the true purpose of the video recordings. It was impossible to blind the occupational therapists (OTs) providing the JP interventions, as it was clear who was going to treat the control patients, i.e. apply the conventional approach and who would treat the experimental patients. It was theoretically possible that OTs exchanged information about the study, as there were two OTs, one 'control and one 'experimental', at each institution, and OT teams per institution are usually small. To reduce this risk, the OTs were informed firstly that this may bias study findings and secondly that there was a true interest in finding out about the effectiveness of individual JP education, no matter if PRISM-based or conventional. We assume that professional ambition stimulated all OTs to provide optimal patient care.

However and most importantly, the outcome assessor of the primary outcome was blinded, as she rated the video sequences without knowing and recognizing the individuals and not either being aware of treatment allocation and time-point of recording.

Standardisation of treatment and avoiding –co-interventions

Our measures to ensure similarity of the JP interventions were: standardisation over the four centres, documentation of additional interventions and not allowing the assessment activity 'preparing instant coffee' as practicing example. Nevertheless, indi-

vidual patients could have received different treatments with different emphases in our RCT, as provided by OTs with different preferences.

Usual medical care to control the RA continued irrespective of treatment arm and the rheumatologists were not aware of the group allocation. Disease activity and the clinical picture are guiding the rheumatologists' decision about drug and drug dose changes (27). Thus it can be assumed that both intervention arms obtained similar medical treatment. As co-interventions were recorded, danger for bias from differences in co-interventions during intervention period was small. In the follow-up period there were some individuals with co-interventions, but similarly in both treatment arms.

Trial execution

Adherence to the trial design is as important as the design itself and includes carrying out correctly the different steps from complying with inclusion/exclusion criteria and randomisation procedure, as well as adherence to treatment protocol, of those providing the intervention and of the patients themselves.

During the intervention period the allocations of the sessions within three weeks needed some adjustment, mostly because it was not possible for the patient due to work or long distance between home and hospital. The 3 months follow-up, i.e. approximately 8 weeks after the intervention period, was performed within a frame of + 2 weeks at maximum; the 6 and 12 months follow-up sessions were performed within a frame of 6 months + 3 weeks and 12 months + 6 weeks. We do not think that these delays introduced any bias, or if, in a random way. It was demonstrated that noticeable changes in habitual JP behaviour may occur due to unpredictable daily pain changes (28, 29), but delays in follow-up assessments occurred in both treatment groups.

Drop outs and loss-to follow-up rates are also critical indicators for the appropriateness of a trial execution and the conclusion drawn from the results. Usually a maximum of 5% is acceptable (1). The rates in our trial were very low. Only one of the 53 patients did not adhere to the interventions. Drop out rate was 0%, loss-to follow-up was 2 patients at 6 months and 2 (other) patients at 12 months.

Study power was based on the results of the D-JPBA-S validation study (29) and calculated cautiously. The low loss-to-follow-up rates helped to achieve the power needed, though the inclusion period needed to be longer than expected.

Intention to treat analysis

Statistical analyses were performed on the intention-to-treat (ITT) principle, i.e. the participants were analyzed by the group they were allocated to by randomisation. Failure to account for all the participants at the inclusion of the trial would result in analysis bias, overestimating the treatment effect. ITT preserves the prognostic balance in the treatment arms achieved by randomization and increases generalisibility. It is a pragmatic and a more conservative estimate of treatment effect and minimizes a type I reporting error.

There were very few missing data, and per assessment time point we had to substitute only one or two patients' scores.

Outcome measures

Valid and reliable health status outcome measurements, well established in the field of rheumatology, were used throughout in this study, including the standard statistical procedures for these instruments, i.e. using sum scores and parametric statistics. Although widely used this way, parametric statistics applied on ordinal scales that are treated as interval scales is reason for concern as to some extend the statistical assumptions are invalid (30). Again, the same score change on a ordinal scale in the lower, middle or upper range of the scale, cannot be assumed to be the same. Not taking this into account, may lead to serious difficulty in the analysis and interpretation of the change scores. It is thus very important to consider the baseline scores to appropriately appraise the change scores. Rasch analysis has been applied on many of these established measures, exploring and demonstrating the problem of ordinal scales and the interpretation of change (31-33). Rasch analysis helps to overcome this by providing estimates of item location (corresponding to item difficulty) on an interval scale based on a logit function. By locating the items on a continuum form less to more (difficult), there is also information about the coverage of the scale; a lack of items at the end(s) of the scale may results in a floor or ceiling effect and lead to under-or overestimation of the clinical relevance of the change (34).

We applied Rasch analysis on the D-JPBA-S assessing the primary outcome and the JP-SES assessing JP self-efficacy, ensuring correct interpretation of change in these two outcomes.

External validity

To be clinically useful, an RCT must provide internal validity, but also external validity. External validity refers to the generalisibility and applicability of the data (35). Lack of external validity is frequently stated as reason why interventions found to be effective in clinical trials are not applied in clinical practice (7). Characteristics of patients, treating centres or health care systems can affect an outcome.

Characteristics of patients

RA-patients needed to have functional impairments (difficulties and/or pain on activity) in wrist and finger joints as important inclusion criteria to the study. Effective drug treatment limited the eligibility of potential participants. However we assumed that only a 'real life' situation, i.e. patients with functional limitations in their hands were referred to JP education, was justifying inclusion to the study.

The restrictive inclusion criteria and additional reasons for not participating (no interest, travel distance, travel ability) made inclusion difficult. In studies that require

quite a lot of commitment, selection bias may occur, as only people who feel a need and are ready for change may participate. This is not of concern, as this also reflects clinical practice where the decision of referring to occupational therapy/JP education is usually made by the rheumatologist and the patient in concordance.

However the effect of the rheumatologists' attitude may be essential as well. Some rheumatologists stated that they generally consider JP not necessary and relevant any more, as either drug treatment was effective or, if not, also JP would not have major impact. This attitude may well influence their patients' decision to take action regarding JP or not, as it has been reported for physical exercise (36, 37).

Characteristics of OTs and care centers

Evidence suggests that patient outcome can be associated with hospital and care providers volume (38). Although this association was particularly examined for surgical procedure, also care outcomes may be influenced by the centers' volume and thus by the experience of the care provider. A survey assessed current clinical practice of JP education among OTs experienced in treating people with RA, from 12 rheumatology clinics and OT private practices. The OTs were invited to participate in a JP intervention study. Six locations agreed and one OT from each place participated in the consensus meeting to standardize the conventional JP education treatment arm. One OT working in her own private practice and the OT from the Zurich League Against Rheumatism (Rheumaliga) finally declined study participation due to their workload; the rehab centre stopped participation after having enrolled only one patient within eight months. Six OTs from three clinics with high volume (two university hospitals, one specialised clinic) participated in the study throughout. This same overall condition reduced bias of possible treatment effect estimates due to number of treated patients. However, it may also indicate that the generalisibility of our findings depend on the OTs' experience and routine.

Comparisons of our RCT with other JP effectiveness studies

The studies by Hammond et al (20, 39, 40) were the first ones that evaluated a psycho-educational approach in JP education. The first study that used the JPBA as objective assessment (28) detected that an educational JP intervention had no effect on JP behaviour. Based on this finding, the following studies were also the first ones applying a psycho-educational approach in JP (group) education. The first study found that psycho-educational JP education (based on the Health Belief Model, self-efficacy theory and strategies to maximise JP adherence including goal-setting, contracting, modelling, homework programmes, motor learning theory, recall enhancing methods and mental practice), was able to improve JP behaviour, but did not achieve significant changes in measures of pain, functional disability, grip strength, self-efficacy or helplessness occurred due to insufficient sample size to detect effectiveness in these outcomes (41). The RCT included a much larger sample (n=127) of people with early RA (disease dura-

tion of <5 years) in order to evaluate effects on health of the (same) psycho-educational group JP programme in comparison with a arthritis education program typical of UK practice (39). The study found significant improvements in JP adherence, arthritis self-efficacy, pain, disease status and functional ability in the participants of the educational-behavioural programme at 12 months follow-up. The positive effects in terms of JP adherence, early morning stiffness and functional ability in daily activities persisted after 4 years (20).

The most important difference in our study was that we provided the JP education in a one-to-one approach and included patients with recent onset and established RA. Although our study had a small sample size, the psycho-educational JP education (PRISM -JP) was able to achieve effects beyond JP behavioural changes, i.e. increased JP self-efficacy and grip strength after 12 months. PRISM-JP thus seemed to be quite a powerful intervention. Interestingly and in contrast to Hammond's studies, conventional JP education improved JP behaviour in the control group. This may be due to the benefits inherent in an individual approach.

Implications for clinical practice

From the systematic review we concluded that only psycho-educational patient education interventions had small effects in the short-term, but none in the long-term. This emphasized the need for using psycho-educational teaching methods and strategies which support long-term adherence in patient education interventions. The interviews with patients about the JP Pros and Cons and the development of the JP self-efficacy scale showed the importance of these cognitions. The RCT demonstrated that in a one-to-one approach JP education increased the use of JP methods, regardless of the teaching methods. However, the psycho-educational intervention was superior in terms of JP behaviour and PRISM demonstrated to be a useful and appreciated tool.

The findings of this research have to be disseminated among the 'final users', i.e. OTs and people with RA and researchers have a certain responsibility for this. Motivational and behavioural approaches should be included in all future JP education interventions. In consequence, extra training in psycho-educational teaching methods, e.g. skills such as problem solving, goal setting and cognitive-behavioural techniques need to be offered, as they are not usual part of most health-care professionals' education in Switzerland. Even, rheumatology care is a 'stepchild' in health professionals' education in this country, and thus an interdisciplinary course in rheumatology care for graduates would be of great value.

We suggest replacing the term 'joint protection' with an alternative term such as 'ergonomic education'. This would more appropriately represent the current concept of providing self-management and coping strategies and not mislead health professionals, referring rheumatologists and patients alike. The implicit suggestion of 'protect the joints' in the present term could be another reason why some rheumatologists are now reluctant to refer patients to occupational therapy.

The time-point for referral of RA patients to allied health professionals is also a controversial issue. It is certainly a matter of resources, but also of philosophy, whether RA is primarily considered as a condition that is treated with effective drugs or as a condition that needs multidisciplinary attention. The actual disease status, as well as the patient's perspective, including his/her stage of disease acceptance and readiness to take action, are important determinants for JP referral. Psycho-educational JP education for patients with early arthritis experiencing hand pain on activity can help maintain their functional ability long-term (20). For early RA patients without pain it would most often not be necessary, or even useless, to provide action-oriented interventions at this stage, but a short PT and OT assessment at this stage may be justified and patients may appreciate information and counseling about disease coping (e.g. strategies to reduce anxiety and concerns about the future), life style (e.g. importance of general physical activity and sport activities) and what kind of help to expect if needed at a later time-points (e.g. health enhancing physical activity and therapeutic exercises, or 'ergonomic education' and assistive devices). Later, when people are recommended occupational therapy, evaluating their Pros and Cons of changing a specific behaviour may be a helpful first step for the patient to decide if these efforts are worthwhile and applicable to him/her. Patients should be referred to action-oriented occupational therapy and ergonomic education when functional problems related to patients' performance in everyday activities occur and when patients perceive a need to actively manage their situation.

No final statement about the duration and amount of 'ergonomic education' can be made. However four sessions and one additional booster session demonstrated to have positive short- and long-term effects. The effect of four 45-minutes sessions in our control group was better than the 2.5-hour JP education of the control group in the trial of Hammond et al. (39). The teaching method (educational or psycho-educational) and the setting (group or individual) seem to be more important than the duration or amount. Distributing the sessions in a weekly rhythm seems adequate, as learning to apply ergonomic methods, problem solving and making adjustments is a behaviour change requiring time.

The booster session two months after the previous interventions was appreciated by the patients, as they could come back and discuss success and problems that occurred in the meantime. We are however not able to draw conclusions about the value (in terms of impact and effectiveness) of this booster session.

In occupational therapy, one of the most used and well-researched models is the Canadian Model of Occupational Performance (CMOP) developed by the Canadian Association of Occupational Therapy (CAOT) (42). The CMOP is concerned with the relationship between occupation, health and well-being and views clients as unique individuals and active participants in therapy. According to the CMOP, the unique contribution of occupational therapy is its focus on *occupational performance, defined as consisting of self-care, productivity, and leisure; being influenced by the environment, one's social roles and one's developmental level; being client-defined; and consisting of both a performance (objective) dimension and a satisfaction (subjective) dimension (43).*

Occupational therapy based on the CMOP thus involves assessment of the abilities and disabilities of the individual client with his/her environment and role expectations (44). The measure derived from the CMOP is the Canadian Occupational Performance Measure (COPM) (45), a patient-centered outcome measure to capture perceived changes in occupational performance. It is performed as a semi-structured interview, where the patient defines his occupational performance problems within *self-care*, *productivity* and *leisure*. Subsequently the importance is rated and the identified most important activities (up to five) are rated on a 1-10 scale regarding their performance (1= not able to do) and satisfaction with performance (1=not satisfied at all with performance). Score calculations are performed to quantify the perceived occupational performance problems.

The functioning of PRISM is thus not very different from the COPM. Both appreciate the underlying philosophy of client-centeredness and their use requires some training. Performing a COPM assessment is a very structured and time-consuming process, whereas the PRISM, despite its systemic approach and the complexity of what it is assessing, allows the therapist – and the patient - to gain a good impression of the overall impact of the illness much more quickly than it would be possible by a structured discussion or a patient narrative (see chapter 6). PRISM facilitates narrative-based practice (46) which aims to focus on the person rather than on the symptoms or illness. The PRISM's open approach may moreover be advantageous because it stimulates the client's perception and reduces thinking in predefined tracks.

It has been demonstrated that these gains are generalisable to other diseases, health professionals and health care systems (47-53). As the use of PRISM is easy and the application is time saving and enriching the therapeutic process with salient information, we recommend its use for routine clinical practice, not only in occupational therapy, but also in physiotherapy, medical consultation and psychological counseling.

Suggestions for further research

Many interesting aspects related to the research of JP education/'ergonomic education' need further attention. However, probably the key question in this context is how to support knowledge transfer and bring the available evidence for the superiority of psycho-educational teaching strategies into routine clinical practice. In her studies, Hammond concluded that psycho-educational JP education has been more successful (in group settings) and, referring to UK practice, repeatedly stated that therefore this approach should be adopted more widely (20, 39). Also in Switzerland, conventional teaching methods are still predominantly applied in routine clinical care.

Evidence based practice (EBP) is the integration of best research evidence with clinical experience and environmental conditions. New evidence may occur and better, more powerful, more accurate or safer concepts and methods should replace previously applied ones. Evidence is however only one element for clinical decision making and it has been suggested to better use the term 'evidence in support of practice' (54) or even 'the evidence in support of a patient decision' (55).

Developing clinical practice guidelines (or translating and adapting existing ones) to guide appropriate and effective clinical practice of occupational therapists involved in the management of people with RA may be of value. Following the Sicily statement (55), patients need to be included in the development of guidelines, in order to make them accessible, readable and understandable for patients as well.

Evidence and recommendations have to find their way to and applied in clinical practice. However, 'nothing implements by itself' and putting evidence into clinical practice should follow a clear implementation strategy (56) and a planned implementation process needs to be established for this. Implementation research first formulates concrete aims of good quality care and analyses the current clinical practice, including influencing facilitators and barriers. As in other research projects, implementation research has then to develop a study plan, methods and measures, based on the aims and analysis. This implementation study is then executed and evaluated.

Hammond et al. disseminated their effective psycho-educational JP intervention nationally and OTs were found to feel confident to apply new JP techniques and thought them useful (57). Lack of knowledge and time, problems with changing routines and lack of financial compensation however have repeatedly been found as barriers, explaining why health professionals not apply new approaches (57-59). Current JP education and facilitators and barriers of applying the psycho-educational strategies need to be evaluated in Switzerland. Based on the aims and the findings, a variety of implementation strategies are available, including educational activities and materials, local protocols to support processes, leadership, team building and patient empowerment. However, as for patient education 'health professional education' requires also attitudinal and behavioural changes of the OTs, and attractive goals, perceived benefit and confidence to change and perform new behaviour may be supportive. Moreover an organisational approach, e.g. collaboration of researchers, clinicians and managers may have important impact (57).

Implementation research will not only evaluate the compliance of professionals (and patients) with the guidelines, but also drive new developments in the field, e.g. define, develop and apply 'outcome measures' (i.e. indicators for documenting the implementation process). It may also drive further rheumatology occupational therapy research.

Drug treatment has been changing the management of RA, including non-pharmacologic interventions, e.g. physiotherapy and occupational therapy. There may be a need to develop and evaluate early non-pharmacologic treatment strategies. RA has lost its terrifying power, however patients still need abilities to deal for a life-time with a disease that may have an unpredictable course. It should be evaluated if early assessment and information/counselling are useful for supporting coping and self-management abilities of RA patients and which strategies and educational and psycho-educational methods and are best in a one-to-one or group setting.

We could not conclude from our study if the booster session, two months after the intervention phase, was beneficial in reinforcing the treatment effects and contributed to the long-term effects found. Booster sessions may be an efficient way to keep

achieved treatment effects in the longer term. Further research is needed, literature so far is scarce and controversial (60, 61)

If it is reasonable to expect long-term changes from short interventions, further ways and determinants of facilitating long-term adherence to the use of alternative ergonomic methods need to be explored.

As demonstrated and discussed, the concept of JP is still important, however, some JP principles may need revision. It is still common advice to exercise with little resistance, but there is increasing evidence that intensive hand exercises are beneficial. They improved hand function and were well-tolerated by people with RA (62). The main concern is to avoid repeated ulnar deviation against resistance during exercise. The current aim of JP education of self-management and coping abilities implies that the patients' perspectives, including their own resources and strategies need to be included to a greater extend. Supporting transfer of ergonomic working methods to individually relevant tasks, individual problem solving and coping strategies may become even more important. The role of OTs will further develop from an expert to a partner and facilitator in the therapeutic process. All these aspects lead to a number of future research topics, e.g. to study the effects of such a patient-centered approach; assess the effects of focused resource activation on motivational processes and outcomes also in group settings or to evaluate the development of the occupational therapy profession.

Last but not least, future research should apply the extended CONSORT statement to Randomized Trials of Nonpharmacologic Treatment (7) when planning, conducting and reporting RCTs. Special attention should be paid to a detailed description of the interventions and the use of established outcome instruments to ensure comparability of studies. The concept of research patient partners is increasingly applied (63, 64). This may help to set research priorities, ensure patient–centered research and improve dissemination and acceptance of research findings.

References

1. van Tulder MW, Assendelft WJ, Koes BW, Bouter LM. Method guidelines for systematic reviews in the Cochrane Collaboration Back Review Group for Spinal Disorders. Spine 1997;22(20):2323-30.
2. Clarke M, Oxman A. Cochrane reviewers' handbook 4.0. Oxford (UK): The Cochrane Collaboration; 1999.
3. Riemsma RP, Kirwan JR, Taal E, Rasker JJ. Patient education for adults with rheumatoid arthritis. Cochrane Database Syst Rev 2003(2):CD003688.
4. Riemsma R, Taal E, Kirwan J, Rasker J. Systematic review of rheumatoid arthritis patient education; 2005.
5. Moher D, Jadad AR, Tugwell P. Assessing the quality of randomized controlled trials. Current issues and future directions. Int J Technol Assess Health Care 1996;12(2):195-208.
6. Boutron I, Tubach F, Giraudeau B, Ravaud P. Blinding was judged more difficult to achieve and maintain in nonpharmacologic than pharmacologic trials. J Clin Epidemiol 2004;57(6):543-50.
7. Boutron I, Moher D, Altman DG, Schulz KF, Ravaud P. Extending the CONSORT statement to randomized trials of nonpharmacologic treatment: explanation and elaboration. Ann Intern Med 2008;148(4):295-309.

8. Christie A, Jamtvedt G, Dahm KT, Moe RH, Haavardsholm EA, Hagen KB. Effectiveness of nonpharmacological and nonsurgical interventions for patients with rheumatoid arthritis: an overview of systematic reviews. Phys Ther 2007;87(12):1697-715.
9. Niedermann K, Fransen J, Knols R, Uebelhart D. The gap between short- and long-term effects of patient education in RA patients: a systematic review. Arthritis Care Res 2004;51(3):388-98.
10. Badamgarav E, Croft JD, Jr., Hohlbauch A, Louie JS, O'Dell J, Ofman JJ, et al. Effects of disease management programs on functional status of patients with rheumatoid arthritis. Arthritis Rheum 2003;49(3):377-87.
11. Astin JA, Beckner W, Soeken K, Hochberg MC, Berman B. Psychological interventions for rheumatoid arthritis: a meta-analysis of randomized controlled trials. Arthritis Rheum 2002;47(3):291-302.
12. Walker D, Adebajo A, Heslop P, Hill J, Firth J, Bishop P, et al. Patient education in rheumatoid arthritis: the effectiveness of the ARC booklet and the mind map. Rheumatology (Oxford) 2007;46(10):1593-6.
13. Mathieux R, Marotte H, Battistini L, Sarrazin A, Berthier M, Miossec P. Early occupational therapy programme increases hand grip strength at 3 months: results from a randomised, blind, controlled study in early rheumatoid arthritis. Ann Rheum Dis 2009;68(3):400-3.
14. Lovisi Neto BE, Jennings F, Barros Ohashi C, Silva PG, Natour J. Evaluation of the efficacy of an educational program for rheumatoid arthritis patients. Clin Exp Rheumatol 2009;27(1):28-34.
15. Giraudet-Le Quintrec JS, Mayoux-Benhamou A, Ravaud P, Champion K, Dernis E, Zerkak D, et al. Effect of a collective educational program for patients with rheumatoid arthritis: a prospective 12-month randomized controlled trial. J Rheumatol 2007;34(8):1684-91.
16. National Collaborating Centre for Chronic Conditions. *Rheumatoid arthritis: national clinical guideline for management and treatment in adults* (Internet). London: Royal College of Physicians, February 2009. (updated 2009 April 29; cited 2009 July 4). Available from http://guidance.nice.org.uk/-CG79/Guidance/pdf
17. Deighton C, O'Mahony R, Tosh J, Turner C, Rudolf M. Management of rheumatoid arthritis: summary of NICE guidance. Bmj 2009;338:b702.
18. Mayoux-Benhamou A, Giraudet-Le Quintrec JS, Ravaud P, Champion K, Dernis E, Zerkak D, et al. Influence of patient education on exercise compliance in rheumatoid arthritis: a prospective 12-month randomized controlled trial. J Rheumatol 2008;35(2):216-23.
19. Masiero S, Boniolo A, Wassermann L, Machiedo H, Volante D, Punzi L. Effects of an educational-behavioral joint protection program on people with moderate to severe rheumatoid arthritis: a randomized controlled trial. Clin Rheumatol 2007;26(12):2043-50.
20. Hammond A, Freeman K. The long-term outcomes from a randomized controlled trial of an educational-behavioural joint protection programme for people with rheumatoid arthritis. Clin Rehabil 2004;18:520-8.
21. Hammond A, Bryan J, Hardy A. Effects of a modular behavioural arthritis education programme: a pragmatic parallel-group randomized controlled trial. Rheumatology (Oxford) 2008;47(11):1712-8.
22. Tennant A, Conaghan PG. The Rasch measurement model in rheumatology: What is it and why use it? When should it be applied, and what should one look for in a Rasch paper? Arthritis Rheum 2007;57(8):1358-62.
23. Bezruczko N. Raw score nonlinearity obscures growth. Rasch Measurement Transactions 2004;18(2):973-974.
24. Wright BD, Linacre JM. Observations are always ordinal; measurements, however, must be interval. Arch Phys Med Rehabil 1989;70(12):857-60.
25. Moher D, Cook DJ, Jadad AR, Tugwell P, Moher M, Jones A, et al. Assessing the quality of reports of randomised trials: implications for the conduct of meta-analyses. Health Technol Assess 1999;3(12):i-iv, 1-98.
26. Wood L, Egger M, Gluud LL, Schulz KF, Juni P, Altman DG, et al. Empirical evidence of bias in treatment effect estimates in controlled trials with different interventions and outcomes: meta-epidemiological study. Bmj 2008;336(7644):601-5.

27. Langenegger T, Fransen J, Forster A, Seitz M, Michel BA. [Clinical quality management in rheumatoid arthritis]. Z Rheumatol 2001;60(5):333-41.
28. Hammond A. Joint protection behavior in patients with rheumatoid arthritis following an education program: a pilot study. Arthritis Care Res 1994;7:5-9.
29. Niedermann K, Forster A, Hammond A, Uebelhart D, de Bie R. Development and validation of a German version of the joint protection behavior assessment in patients with rheumatoid arthritis. Arthritis Rheum 2007;57(2):249-55.
30. Merbitz C, Morris J, Grip JC. Ordinal scales and foundations of misinference. Arch Phys Med Rehabil 1989;70(4):308-12.
31. Tennant A, Hillman M, Fear J, Pickering A, Chamberlain MA. Are we making the most of the Stanford Health Assessment Questionnaire? Br J Rheumatol 1996;35(6):574-8.
32. Stucki G, Daltroy L, Katz JN, Johannesson M, Liang MH. Interpretation of change scores in ordinal clinical scales and health status measures: the whole may not equal the sum of the parts. J Clin Epidemiol 1996;49(7):711-7.
33. Pallant JF, Tennant A. An introduction to the Rasch measurement model: an example using the Hospital Anxiety and Depression Scale (HADS). Br J Clin Psychol 2007;46(Pt 1):1-18.
34. Haley SM, McHorney CA, Ware JE, Jr. Evaluation of the MOS SF-36 physical functioning scale (PF-10): I. Unidimensionality and reproducibility of the Rasch item scale. J Clin Epidemiol 1994;47(6):671-84.
35. Ahmad N, Boutron I, Moher D, Pitrou I, Roy C, Ravaud P. Neglected external validity in reports of randomized trials: The example of hip and knee osteoarthritis. Arthritis Rheum 2009;61(3):361-9.
36. Iversen MD, Eaton HM, Daltroy LH. How rheumatologists and patients with rheumatoid arthritis discuss exercise and the influence of discussions on exercise prescriptions. Arthritis Rheum 2004;51(1):63-72.
37. Iversen MD, Fossel AH, Ayers K, Palmsten A, Wang HW, Daltroy LH. Predictors of exercise behavior in patients with rheumatoid arthritis 6 months following a visit with their rheumatologist. Phys Ther 2004;84(8):706-16.
38. Halm EA, Lee C, Chassin MR. Is volume related to outcome in health care? A systematic review and methodologic critique of the literature. Ann Intern Med 2002;137(6):511-20.
39. Hammond A, Freeman K. One-year outcomes of a randomized controlled trial of an educational-behavioural joint protection programme for people with rheumatoid arthritis. Rheumatology (Oxdford) 2001;40:1044-51.
40. Hammond A, Lincoln N. The effect of a joint protection education programme for people with rheumatoid arthritis. Clin Rehabil 1999;13:392-400.
41. Hammond A, Lincoln N, Sutcliff L. A crossover trial evaluating an educational-behavioural joint protection programme for people with rheumatoid arthritis. Patient Educ Couns 1999;40:1044-51.
42. CAOT CAoOT. Enabling Occupation: An Occupational Tehrapy Perspective.; 1997.
43. McColl MA, Paterson M, Davies D, Doubt L, Law M. Validity and community utility of the Canadian Occupational Performance Measure. Can J Occup Ther 2000;67(1):22-30.
44. Kjeken I. Participation, involvement and functional assessment in rheumatology care: PhD thesis, University of Oslo; 2006.
45. Law M, Baptiste S, Carswell A, Mc Coll M, H. P, Pollock N. Canadian Occupational Performance Measure (Manual). 3rd ed: CAOT Publications ACE; 1998.
46. Frank A. The Wounded Storyteller, Body, Illness and Ethics. Chicago: The University of Chicago Press; 1995.
47. Wouters EJ, Reimus JL, van Nunen AM, Blokhorst MG, Vingerhoets AJ. Suffering quantified? Feasibility and psychometric characteristics of 2 revised versions of the Pictorial Representation of Illness and Self Measure (PRISM). Behav Med 2008;34(2):65-78.
48. Streffer ML, Buchi S, Morgeli H, Galli U, Ettlin D. PRISM (pictorial representation of illness and self measure): a novel visual instrument to assess pain and suffering in orofacial pain patients. J Orofac Pain 2009;23(2):140-6.

49. Reinhardt S, Bischof G, Grothues J, John U, Rumpf HJ. Performance of the pictorial representation of illness and self measure in individuals with alcohol dependence, alcohol abuse or at-risk drinking. Psychother Psychosom 2006;75(4):249-56.
50. Klis S, Vingerhoets AJ, de Wit M, Zandbelt N, Snoek FJ. Pictorial Representation of Illness and Self Measure Revised II (PRISM-RII): a novel method to assess perceived burden of illness in diabetes patients. Health Qual Life Outcomes 2008;6:104.
51. Kassardjian C, Gardner-Nix J, Dupak K, Barbati J, Lam-McCullock J. Validating PRISM (Pictorial Representation of Illness and Self Measure) as a measure of suffering in chronic non-cancer pain patients. J Pain 2008;9(12):1135-1143.
52. Buchi S, Morgeli H, Schnyder U, Jenewein J, Hepp U, Jina E, et al. Grief and post-traumatic growth in parents 2-6 years after the death of their extremely premature baby. Psychother Psychosom 2007;76(2):106-14.
53. Buchi S, Buddeberg C, Klaghofer R, Russi E, Brandli O, Schlosser C, et al. Preliminary validation of PRISM (Pictorial Representation of Illness and Self Measure) - a brief method to assess suffering. Psychotherapy & Psychosomatics 2002;71:333-41.
54. Davidoff F. In the teeth of the evidence: the curious case of evidence-based medicine. Mt Sinai J Med 1999;66(2):75-83.
55. Dawes M, Summerskill W, Glasziou P, Cartabellotta A, Martin J, Hopayian K, et al. Sicily statement on evidence-based practice. BMC Med Educ 2005;5(1):1.
56. van Hulst LT, Fransen J, den Broeder AA, Grol R, van Riel PL, Hulscher ME. Development of quality indicators for monitoring of the disease course in Rheumatoid Arthritis. Ann Rheum Dis 2009.
57. Hammond A, Klompenhouwer PJ. Getting evidence into practice: implementing a behavioural joint protection education programme for people with rheumatoid arthritis. Br J Occup Ther 2005;68(1):25-33.
58. Pollock AS, Legg L, Langhorne P, Sellars C. Barriers to achieving evidence-based stroke rehabilitation. Clin Rehabil 2000;14(6):611-7.
59. Niedermann K, Fransen J, Huber E, Uebelhart D, Steiner W. Einstellungen und Arbeitsweise von PhysiotherapeutInnen - Begleitevaluation zum Outcome-Projekt 2000-2001. FISIOactive (J of Swiss PT association) 2002;7:4-13.
60. Brus H, van-de-Laar M, Taal E, Rasker J, Wiegman O. Effects of patient education on compliance with basic treatment regimens and health in recent onset active rheumatoid arthritis. Ann-Rheum-Dis 1998;6(4):213-22.
61. Wiskin L. Cognitive-behavioral therapy: a psychoeducational treatment approach for the American worker with rheumatoid arthritis. Work 1998;10(1):41-48.
62. Ronningen A, Kjeken I. Effect of an intensive hand exercise programme in patients with rheumatoid arthritis. Scand J Occup Ther 2008;15(3):173-83.
63. Kirwan JR, Ahlmen M, de Wit M, Heiberg T, Hehir M, Hewlett S, et al. Progress since OMERACT 6 on including patient perspective in rheumatoid arthritis outcome assessment. J Rheumatol 2005;32(11):2246-9.
64. Kirwan J, Heiberg T, Hewlett S, Hughes R, Kvien T, Ahlmen M, et al. Outcomes from the Patient Perspective Workshop at OMERACT 6. J Rheumatol 2003;30(4):868-72.

English Summary
Deutsche Zusammenfassung
Nederlandse Samenvatting

Summary

This PhD thesis is about joint protection education in people with rheumatoid arthritis (RA). This included seven scientific articles, presented in the chapters 2-8.

Chapter 1 introduces to the field and outlines the rationale for joint protection education in people with RA. Musculoskeletal disorders are the most common cause of chronic disorders. RA is a chronic systemic disease with both short and long-term impacts. Prevalence is 0.8-1% and mostly RA affects people of working age. Thus, despite the relatively low prevalence rate, the economic consequences of the disease are considerable. The course of the disease is unpredictable; it may be intermittent, but is generally progressive. Disease activity is associated with painful inflammation, which may lead to joint destruction and deformity, and functional loss. This may impose a number of limitations and restrictions on patients' daily activities but also on their relationships (family, friends), work participation (remunerative and non-remunerative) and engagement in leisure time and social activities. All of these may seriously affect their quality of life.

Drug therapy nowadays aims to control disease activity and thus destruction processes, i.e. complete remission, and impressive advances have been achieved over the last 10 -15 years. Drug treatment includes early treatment, tight control, drug combinations and the introduction of the highly effective treatment with biologicals, such as anti-TNF and Rituximab. However, about one third of RA patients does not respond sufficiently on any available drug, quite a number of patients may also discontinue TNF treatment due to serious side effects. There are also patients with established RA who already developed secondary osteoarthritis and joint deformities prior to the time when the more effective biologicals became available. Therefore, a comprehensive multidisciplinary approach remains state-of-the art. Physiotherapy and occupational therapy both aim to maintain or improve functional abilities and thus independence and quality of life.

In patients developing functional impairment, hand involvement is still one of the major problems. Rating the priorities, hand and finger improvement reached the second highest ranking, behind pain improvement. In 2001, 41.6% of RA patients rated hand and finger improvements as most relevant, compared to 45% in 1994. Hand JP education is therefore still a key intervention.

The modern joint protection (JP) concept for people with RA is an active coping strategy to improve daily tasks and role performance by changing working methods and using assistive devices. The JP aims associated with this self-management approach

require psycho-educational teaching strategies, i.e. methods that facilitate behavioural change and self-management. In Switzerland however, JP education is usually provided in a one-to-one setting and mostly applies purely educational strategies, providing knowledge and skills. There is evidence for the effectiveness of group JP education applying psycho-educational approaches. It was unclear whether the evidence for psycho-educational group JP education was applicable to an individual JP education.

Chapter 2 (Gap between short- and long-term effects of patient education in rheumatoid arthritis patients) presents a systematic review that was performed to establish the evidence of patient education in people with RA. Studies were selected among the randomized controlled trials (RCTs) published between 1980 and July 2002, available on Medline, Psychlit, CINAHL and Cochrane data-base. Additionally, the citation lists in relevant publications were checked to complete the selection. A total of 63 studies evaluating patient education interventions were identified. Eleven studies fulfilled all of the given selection criteria and were therefore included in this review. Two reviewers independently appraised their methodological quality using the validity criteria from the Amsterdam-Maastricht Consensus List for Quality Assessment and the criteria set in the Cochrane Reviewers' Handbook for data extraction criteria. According to these criteria, a total of seven studies met most of these requirements and were considered high-quality studies, whereas the four other studies were considered poorly designed. To decide about the strength of evidence for patient education, the outlines of van Tulder et al. were followed. Special attention was paid to the distinction between short-term and long-term effectiveness of RA patient education. There was a great variety of interventions, program durations, outcome measures, and follow-up periods. The findings in our review were two-fold: 1) the gap between educational and psycho-educational interventions and 2) the gap between short-term and long-term effects. From this systematic review we concluded that only psycho-educational patient education interventions had small effects in the short-term, but very few in the long-term. This also supported the need for using psycho-educational teaching methods and for strategies which support long-term adherence in JP interventions. One of the studies included in the review, the study by Hammond et al (1999), found that psycho-educational teaching strategies could facilitate JP adherence, suggesting that this approach should be more widely adopted in clinical practice.

Chapter 3 (Development and validation of a German version of the Joint Protection Behaviour Assessment in patients with rheumatoid arthritis) describes the validation process of an assessment to evaluate JP behaviour. Earlier JP studies applied questionnaires and found self-reported improvement in JP. However, self-reporting tends to overestimate behaviour and report attitudes and perceptions, rather than the behaviour itself. For this reason, the Joint Protection Behavioural Assessment (JPBA), a video assessment of the use of JP methods while preparing instant coffee and a snack meal, had been developed (Hammond et al, 1999). The JPBA allowed to systematically and

objectively evaluate effectiveness of JP interventions and marked a major step in the assessment of JP behaviour.

We performed a cross-cultural adaption of the short version of the JPBA (JPBA-S), including only the task 'preparing instant coffee' in a German-speaking Swiss RA population. The validation procedure for the D-JPBA-S included the development of an assessment manual and the evaluation of the psychometric properties. The manual was developed through consensus with eight occupational therapist (OT) experts as the reference for assessing patients' JP behavior. Twenty-four patients with RA and 10 healthy individuals were videotaped while performing the 10 tasks reflecting the activity of 'preparing instant coffee'. Recordings of patients were repeated after 3 months for test–retest reliability and assessed by one rater. The video recordings of 10 randomly selected patients and all healthy individuals were independently assessed for inter-rater reliability by 6 OTs. All raters were explicitly asked to follow the manual. Rasch analysis, an innovative statistical approach, was performed to test construct validity and transform ordinal raw data into interval data for reliability calculations. Nine of the 10 tasks fit the Rasch model. The D-JPBA-S, consisting of 9 valid tasks, had an intraclass correlation coefficient of 0.77 for interrater reliability and 0.71 for test–retest reliability. Thus, the D-JPBA-S provided a valid and reliable instrument for assessing JP behavior in German-speaking people with RA.

Chapter 4 (Perceived benefits and barriers to joint protection among people with rheumatoid arthritis and occupational therapists) presents a study that applied a mixed methods design, i.e. the combined use of questionnaires and focussed interviews to evaluate the perceptions of the benefits of and barriers to using JP methods in people with RA and in OTs. The concept of decision making represents a gain-versus-loss model, balancing the benefits and barriers towards a behaviour. The balancing of the benefits and barriers is considered a critical process in changing behaviours or adhering to new behaviours. Also the attitudes health professionals hold towards a specific behaviour influence how much they motivate people to change and whether people correspondingly then adhere to that behaviour.

The questionnaires detected that both groups, RA participants and OTs, agreed that highly relevant JP benefits were *'physical well-being', 'potential benefit'*, and *'personal control.'* In contrast, the JP barriers: *'negative attitude of others'*, *'negative impact on others'* and *'taking time from other things'* were relevant for the majority of the OTs but not for the RA participants. The interviews enabled understanding the meaning behind participants with RA ratings, particularly their differences to OTs. People with RA explained JP benefits and disease acceptance had altered some initial barriers into perceived benefits over time. The study suggested that emphasizing benefits and identifying individually relevant barriers could be an important communication strategy for OTs in understanding patients' rationale for adopting or not adopting JP methods.

Chapter 5 (Development and Psychometric Properties of a Joint Protection Self-Efficacy Scale (JP-SES) using Rasch analysis) presents the development and validation process of a JP specific self-efficacy instrument. Self-efficacy is considered as one of the most powerful determinants for acquiring, performing and adhering to a (new) behaviour. It is defined as the confidence of a person to successfully execute a future specific behaviour or task (i.e. (self)-efficacy expectation) and the person's belief that the desired behaviour has a positive effect (i.e. outcome expectation). Self-efficacy is acquired by direct experience, vicarious experience (role modelling), verbal persuasion and reinterpretation of physiological signals. Direct experience is far more effective than indirect experience.

Achieving the long-term aim of JP as an active coping strategy to improve daily tasks and role performance requires psycho-educational methods. In this JP education approach, practice under supervision and at home, goal setting and feedback, observing and exchange with peers in groups, discussions and verbal persuasion are important strategies. These learning and practice situations to acquire JP behaviours are also the four sources for acquiring self-efficacy. To facilitate this, a specific JP self-efficacy scale may assist in guiding the therapeutic approach of JP education by evaluating and supporting the patients' belief in their ability to acquire, perform and adhere to JP behaviour.

The aim of this study was therefore to develop a scale to measure JP self-efficacy (JP-SES) in people with RA. Instrument development included item generation, construct validity and reliability testing. Rasch analysis was applied to determine construct validity and the revised JP-SES was tested again to confirm validity and establish test-retest reliability and internal consistency. Fourty-six items were generated by literature review, occupational therapists and people with RA. After semi-structured interviews and field-testing with RA participants, a 26-item questionnaire was constructed and tested. Rasch analysis to determine construct validity reduced the JP-SES to 13 items with good overall fit values. Rasch analysis of confirmatory validity resulted in a 10-item version of the JP-SES. Test-retest results supported the validity of the scale, with high internal consistency (alpha=0.92) and good test-retest reliability (r_s= 0.79; p<0.001). By this step by step procedure the JP-SES provided a valid and reliable scale to assess perceived ability of people with RA to apply JP methods.

Chapter 6: Enhancing Communication of Patient's Illness Experience Facilitates Therapeutic Process: Two Case Studies Using PRISM (Pictorial Representation of Illness and Self Measure) contains two case studies that demonstrate the application of the PRISM. PRISM is a novel and brief interactive hands-on-tool. It maps the relationships between illness and other aspects of the patient's life by assessing a) the individual's perceived burden of illness and b) relevant individual life areas being resources. Both issues may be important determinants for motivation and behavioural change. When performing the *PRISM task*, the patient is shown a white A4-sized board with a fixed yellow disk (7cm in diameter) at the bottom right corner. S(he) is asked to imagine the board represents his/her life as it currently is, and the disk his/her "Self". The person is then handed

a red disk, 5 cm in diameter, representing his/her "Illness" and asked where (s)he would put the Illness disk to reflect the burden of illness in his/her life at present. The quantitative measure is the "Self-Illness Separation" (SIS), the distance between the centres of the "Illness" and the "Self" disks (range 0-27 cm), with a smaller distance indicating higher impact of the illness (see Figure 1a in chapter 7). For the *PRISM+ task* further disks, similar to the illness disk but of different colours, can be used to represent a patients' resources (e.g. leisure activities, family/friends, work). The SRS (Self-Resource-Separation) is used accordingly, i.e. the distance between the centres of a "Resource" and the "Self" disks (range 0-27 cm). However, the SRS has to be interpreted differently than the SIS: larger distances indicate a less positive impact of the resource, whilst smaller distances indicate a more positive impact (see Figure 1b in chapter 7)

In routine clinical care PRISM had demonstrated high therapeutic potential. The cases demonstrated that the application of PRISM was simple and powerful. It optimized and accelerated therapeutic processes and enhanced patient-therapist communication of individual aspects of illness.

Chapters 7 and 8 present the results of our RCT that aimed to compare the short- and long-term effects of individual PRISM-based JP education (PRISM-JP) with conventional JP education (C-JP) in people with RA. Participants were eligible when: diagnosed with RA according to ACR (American College of Rheumatology) guidelines; with functional impairments (difficulties and/or pain on activity) in wrist and finger joints justifying occupational therapy, and had sufficient German language skills. Severe finger, hand and shoulder joint deformities were exclusion criteria, as these can lead to difficulty performing common JP methods and require more idiosyncratic solutions. When RA patients were asked to participate they were informed that the aim was to evaluate two different educational approaches within occupational therapy; the focus on JP behaviour however was not mentioned. The trial was conducted in four rheumatology centres in the German part of Switzerland. When preparing this study, a consensus meeting with all OTs involved was held to standardise the JP education of the four participating institutions. There was little disagreement on content and delivery, i.e. individual setting and use of (traditional) teaching methods, as representing typical practice in Switzerland. Both C-JP and PRISM-JP were defined as four 45-minutes one-on-one JP education sessions over three weeks and an additional booster session two months later.

Patients were randomized to either PRISM-JP or C-JP. C-JP consisted of the standardised JP education by use of traditional teaching methods. This was summarised in a short manual: oral and written information about RA and JP principles; demonstrations and supervised practice of hand JP methods, mostly in a kitchen activity, and demonstration of appropriate assistive devices. The OTs were free to provide the elements within the five sessions.

The PRISM-JP also consisted of the standardised JP education, but was much more individualised, and based on the PRISM tasks (PRISM / PRISM+), the theories of social learning and self-management. The PRISM-JP content was allocated to sessions 1 to 4.

In *session 1 of PRISM-JP,* the PRISM task was used to assess perceived impact of the RA or RA-related pain and identify individual JP education goals. This client-centred approach helped to select individually meaningful rather than purposeful occupations in conventional JP education, such as usual household or self-care activities.

In *session 2,* The PRISM+ task helped find the most important individual resource. Patients were asked to choose one single resource with a most positively perceived impact, which they wanted to foster during therapy such as listening/playing music or going to cinema and meeting friends. This resource was deliberately selected not to be in any connection to illness-related problems and JP activities. The aim was to improve the positive impact of the selected activity and thus to enhance patients' motivation for collaboration. In *sessions 3 and 4*, the positive impact of the resource was evaluated and reinforced.

JP education and practice became progressively complex in the course of the therapy sessions, starting with self-monitoring of hand use and activities causing pain and difficulties; proceeding onto selecting one or several JP principle(s) to applying (referring to life areas defined in session 1) and practicing JP methods within individually selected complex activities and discussing and applying transfer of JP methods to other activities, energy conservation, the balance between activity and rest.

Homework, goal setting and self-monitoring were important further parts of PRISM-JP.

Comprehensive Assessments were performed at baseline, at 3 months (before the booster session) and at 6 and 12 months. The primary outcome *Joint protection behaviour* was evaluated using the German version of the Joint Protection Behaviour Assessment D-JPBA-S. Patients were kept blind about the true purpose of the video recording to ensure habitual performance. Light conversation was continued to distract from paying conscious attention to hand use. One rheumatology OT, who was kept blind to patients' treatment allocation and time-point of recording, rated all assessments following the instructions of the D-JPBA-S manual. A number of functional, disease-specific and psychological assessments were performed to evaluate secondary outcomes.

Chapter 7: Effectiveness of an individualized resource-oriented joint protection education in people with rheumatoid arthritis presents the short-term results of the randomised controlled trial (RCT), i.e. after 3 months. A total of 53 RA patients participated in this RCT. We found that both groups improved their JP behaviour ($p<0.000$), but the PRISM-JP group improved significantly more ($p=0.008$). In this group, especially people who did not perform JP previously, could get the most gain from JP education. The participants of the PRISM group also had more arthritis self-efficacy (ASES $p=0.015$) and JP self-efficacy (JP-SES $p=0.047$). Within-group analysis also showed less hand pain ($p<0.001$) in PRISM-JP group. We concluded that an individualised intervention based on the PRISM approach could increase behavioural and psychological benefits of JP education and possibly have positive effects on patients' motivation.

Chapter 8 (Six and 12 months' effects of individual joint protection education in people with rheumatoid arthritis: A randomized controlled trial) presents the long-term results after 6 and 12 months. At these long-term follow-ups, both groups showed increased JP behaviour ($p<0.000$) compared to baseline; but the PRISM-JP group (n=26) did significantly better at 6 ($p=0.018$) and 12 months ($p=0.038$). JP self-efficacy (JP-SES) was improved in both groups at 6 months ($p=0.03$). Within group analysis at 12 months showed that the PRISM-JP group had better JP self-efficacy ($p=0.02$) and grip strength ($p=0.04$) and perceived less disease activity ($p=0.05$).

We concluded that, in contrast to group JP education, a one-on-one setting improved JP behaviour significantly regardless of the teaching strategy. However, PRISM-JP more effectively supported learning of and adherence to JP methods. The more pronounced use of JP methods in the PRISM-JP group was associated with long-term effects in grip strength, JP self-efficacy and perceived disease activity.

Chapter 9 finally contains a general discussion on several aspects of this thesis. It encompasses three parts. The first part summarises and discusses the methodology and the validity of the different studies.

The second suggests implications of these findings for further clinical care. The use of psycho-educational methods to enable behavioural changes is recommended, including PRISM for routine clinical practice, not only in occupational therapy, but also in physiotherapy, medical consultation and psychological counselling. Further we suggest replacing the term 'joint protection' with an alternative term such as 'ergonomic education', which may more appropriately represent the current concept of providing self-management and coping strategies and not mislead health professionals, referring rheumatologists and patients alike by the implicit suggestion of 'protect the joints'. Based on our results and on results from other previous studies, the need for clear implementation strategies to translate study findings into clinical practice is highlighted and discussed.

The third and last part concludes with ideas for future research in the field of JP education and behavioural change and emphasised the need for methodically sound studies.

Zusammenfassung

Diese PhD Arbeit befasst sich mit Gelenkschutz bei Personen mit Rheumatoider Arthritis (RA). Sie beinhaltet sieben wissenschaftliche Arbeiten, die in den Kapiteln 2-8 präsentiert werden.

Kapitel 1 führt in das Thema ein und begründet den Gelenkschutz bei RA.
Muskuloskeletale Beschwerden sind der häufigste Grund für chronische Beschwerden. RA ist eine chronisch-systemische Erkrankungen mit Kurz- und Langzeitfolgen. RA tritt in ca 0.8-1% der Bevölkerung auf und trifft meistens Personen im arbeitsfähigen Alter. Trotz der relativ kleinen Zahl von Betroffenen sind deshalb die oekonomischen Konsequenzen der RA beträchtlich. Der Verlauf der RA ist unvorhersehbar: sie verläuft oft schubweise und ist im Allgemeinen fortschreitend. Aktive RA zeigt sich in schmerzhaften Entzündungen, die zu Destruktionen und Deformierungen der Gelenke und zu funktionellen Einschränkungen führen können. Das kann für Betroffene zu einer Reihe von Beeinträchtigungen bei ihren Alltagsaktivitäten, aber auch ihren sozialen Beziehungen (Familie, Freunde), ihrer Arbeitsfähigkeit (entlöhnte und nicht –entlöhnte), und ihrer sozialen Partizipation (Freizeit- und soziale Aktivitäten) führen und damit ihre Lebensqualität stark beeinträchtigen.

Medikamentöse Therapie kann heutzutage eine vollständige Remission erreichen, d.h. die Krankheitsaktivität und damit den Destruktionsprozess in den Gelenken vollständig unterdrücken. In den letzten 10-15 Jahren wurden mit früher Behandung, engmaschiger Überwachung, Kombinationstherapien und der Einführung einer neuen Generation von hochwirksamen Medikamenten, den sogenannten Biologikas (TNF alpha, Rituximab), eindrückliche Fortschritte erzielt. Trotz alldem, rund ein Drittel der RA-Betroffenen reagiert nicht oder nur ungenügend auf die verfügbaren Medikamente und eine weitere Anzahl Betroffener muss die Therapie mit Biologoikas wegen ernsthafter Nebenwirkungen abbrechen. Im weiteren gibt es Betroffene, bei denen die RA schon vor der Ära der wirksamen Biologikas auftrat und bei denen sich bereits Gelenksschäden entwickelt haben. Ein umfassendes multidisziplinäres Management der RA ist deshalb nach wie vor State-of-the-Art. Darin haben Physiotherapie und Ergotherapie zum Ziel, die funktionellen Fähigkeiten und damit die Unabhängigkeit und Lebensqualität zu erhalten oder zu verbessern

Bei RA Patienten mit funktionellen Problemen ist die Beteiligung der Hände immer noch eines der grössten und häufigsten Probleme. Betroffene nennen die Verbesserung der Hand- und Fingerfunktion, nach der Schmerzreduktion, als die 2. Priorität. 2001 war für 41,6 % der RA-Betroffenen Verbesserungen von Handfunktionen am wichtigsten –

eine nur kleine Veränderung im Vergleich zu 1994 als 45% der RA-Betroffenen Hand-Fingerfunktion als am wichtigsten nannten. Hand-Gelenkschutz Edukation gilt deshalb als eine Schlüsselintervention.

Das moderne Konzept von Gelenkschutz (GS) bei RA-Betroffenen ist eine aktive Bewältigungsstrategie (sogenanntes Coping), um die täglichen Aktivitäten und sozialen Rollen zu meistern, durch Ändern von Arbeitsmethoden und Einsetzen von Hilfsmitteln. Um die mit diesem Selbstmanagement-Konzept verbundenen Gelenkschutz-Ziele zu erreichen, sind psycho-edukative Methoden notwendig. Das sind Lehr-Methoden, die insbesondere Verhaltensänderung und Selbstmanagement fördern, und nicht nur Wissen und Fertigkeiten vermitteln (= edukative Methoden). In der Schweiz wird Gelenkschutz zumeist im Rahmen von Ergotherapie-Einzelsitzungen mit edukativen Methoden vermittelt. Es gibt Evidenz für die Wirksamkeit von Gelenkschutz-Edukation mit psycho-edukativem Ansatz in Gruppensettings. Es ist bisher nicht untersucht, ob diese Evidenz auch in Einzeltherapie-Settings übertragbar ist.

Kapitel 2 (Gap between short- and long-term effects of patient education in rheumatoid arthritis patients) präsentiert eine systematische Literatur-Review, welche die Evidenz für *Patient Education bei RA-Betroffenen* untersuchte. Es wurden randomisierte, kontrollierte Studien eingeschlossen, die zwischen 1980 und 2002 publiziert und in den medizinischen Datenbanken Medline, Psychlit, CINAHL and Cochrane zu finden waren. Zusätzlich wurden die Referenzlisten von einschlägigen Publikationen überprüft, um die Auswahl zu ergänzen.

Von den anfänglich 63 identifizierten Studien über Patient Education Interventionen bei RA erfüllten elf die beschriebenen Selektionskritierien und wurden in die Review eingeschlossen. Zwei Gutachter beurteilten unabhängig voneinander die methodologische Qualität der Studien. Sie verwendeten dafür die *Validitätskritierien* der Amsterdam-Maastricht Consensus Liste für Qualitäts-Assessment und die *Kritierienliste für Datenextraktion* im Cochrane Reviewers Handbuch. Sieben Studien erfüllten die meisten dieser Kriterien und galten damit als Studien von hoher Qualität. Die vier anderen Studien hatten mangelhafte methodologische Qualität. Die Stärke der Evidenz für Patient Education wurde anhand der Richtlinien von van Tulder et al. beurteilt. Spezielle Aufmerksamkeit erhielt die Unterscheidung von kurz- und langfristiger Wirksamkeit. Es gab eine grosse Vielfalt von Interventionen, Programmdauer, gemessenen Endpunkten und Nachuntersuchungs- Perioden. Unsere Review fand zwei wichtige Ergebnisse: 1) die Diskrepanz zwischen edukativen und psycho-edukativen Interventionen und 2) die Diskrepanz zwischen kurz- und langfristiger Wirksamkeit. Wir folgerten daraus, dass nur psycho-edukative Patient Education Interventionen Effekte erreichten, und zwar vor allem Kurzzeiteffekte, aber nur sehr wenige Langzeiteffetkte. Das stützte die Forderung nach psycho-edukativen Methoden und nach Interventionen und Strategien, welche das langfristige Anwenden von (neuen) Verhaltensweisen (sogenannte Adhärenz) ermöglichen. Eine der eingeschlossenen Studien (Hammond et al 1999) fand, dass psycho-edukative Srategien in der Gelenkschutz-Edukation möglicherweise die Adhärenz fördern, und empfahl eine breite Anwendung dieses Ansatzes in der Gelenkschutz-Edukation.

Kapitel 3 (Development and validation of a German version of the Joint Protection Behaviour Assessment in patients with rheumatoid arthritis) beschreibt den Validierungsprozess eines Messverfahrens für Gelenkschutz-Verhalten. Frühere Gelenkschutz-Studien verwendeten Fragebogen und konnten damit verbessertes Gelenkschutz-Verhalten nachweisen. Allerdings tendieren Aussagen in Patienten-Fragebogen zu einer Überschätzung und geben eher Wahrnehmungen und Einstellungen gegenüber dem Verhalten als das Verhalten selbst wider. Aus diesem Grund war von Hammond et al das Joint Protection Behavioural Assessment (JPBA) entwickelt worden, ein Verfahren, das Gelenkschutz-Verhalten Video-gestützt beobachtet während der Aktivitäten ‚Instant Kaffee und einen Snack zubereiten'. Das JPBA erlaubt die systematische und objektive Evaluation von Gelenkschutz-Interventionen und war ein bedeutender (Fort-)Schritt im Messen von Gelenkschutz-Verhalten.

Wir führten eine cross-kulturelle Adaptation der englischen Kurzversion (des JPBA-S) in einer deutschsprachigen Schweizer RA Population durch. Das JPBA-S enthält nur die Aktivität ‚Instant Kaffee zubereiten'. Das Validierungsprozedere für die deutsche Version, das D-JPBA-S, umfasste die Entwicklung eines Manuals, das für zehn Aufgabe während der Aktivität ‚Instant Kaffee zubereiten' die Kritierien zum Beurteilen des Gelenkschutz-Verhaltens enthielt. Das Manual wurde in einem Konsens-Prozess mit acht in Rheumatologie erfahrenen Ergotherapeutinnen entwickelt. Anschliessend wurden die psychometrischen Eigenschaften des D-JPBA-S evaluiert, Dafür wurden 24 RA-Betroffene und zehn gesunde Probanden beim Zubereiten von Instant Kaffee gefilmt. Die Aufnahmen wurden drei Monate später für eine Test-Retest Analyse wiederholt und von einer Beurteilerin beurteilt. Die Videoaufnahmen von zehn zufällig ausgewählten Patienten und allen zehn gesunden Probanden wurden von sechs ErgotherapeutInnen unabhängig voneinander beurteilt und in Bezug auf die sogenannte Inter-Rater-Reliabilität, d.h. der Übereinstimmung zwischen den Beurteilerinnen, analysiert. Die Beurteilerinnen waren explizit aufgefordert, den Kriterien im Manual zu folgen. Die Konstrukt-Validität wurde mit der sogenannten Rasch Analyse beurteilt, d.h. es wurde untersucht, ob alle zehn Aufgaben der Aktivität Înstant Kaffee zubereiten' auch tatsächlich Aussagen über das Gelenkschutzverhalten erlauben. Im weiteren transformiert die Rasch Analyse kategorielle Daten in Intervalldaten und erlaubt damit parametrische Statistik. Neun der zehn Aufgaben passten ins Raschmodell, d.h. sie massen tatsächlich Gelenkschutzverhalten. Die definitive Version des D-JPBA-S besteht aus neun Aufgaben, mit einer Übereinstimmung von 77% zwischen den Beurteilerinnen und einer Zuverlässigkeit von 71% bei Testwiederholung. Damit steht ein valides und reliables Instrument zur Messung von Gelenkschutzverhalten bei deutschsprachigen RA-Betroffenen zur Verfügung.

Kapitel 4 (Perceived benefits and barriers to joint protection among people with rheumatoid arthritis and occupational therapists) präsentiert eine Studie, die untersuchte welche Förderfaktoren und Barrieren für Gelenkschutzverhalten RA-Betroffene und Ergotherapeutinnen wahrnehmen. Wir wendeten einen sogenannten ‚mixed-methods' Ansatz an, d.h. die Kombination von Fragebogen und fokussierten Interviews.

Das Konzept der Entscheidungsfindung ist ein Gewinn-versus-Verlust Modell, das Vorteile und Nachteile eines Verhaltens einander gegenüberstellt. Dieses oft unbewusste Abwägen gilt als kritischer Prozess für Verhaltensänderungen und die Adhärenz an neue Verhaltensweisen. Auch die Einstellung von Health Professionals gegenüber einem spezifischen Verhalten beeinflussen wie stark sie Betroffene zur Verhaltensänderung motivieren und sie in der Adhärenz unterstützen.

Die Fragebogen zeigten, dass RA-Betroffene und Ergotherapeutinnen sich einig waren, über fördernde Faktoren für Gelenkschutzverhalten: *‚körperliches Wohlergehen, potentieller Nutzen* und *persönliche Kontrolle'*. Im Unterschied dazu waren die Barrieren für Gelenkschutzverhalten *‚negative Haltung von anderen', ‚negativer Einfluss auf andere'* und *‚weniger Zeit für anderes'* für eine Mehrheit der Ergotherapeutinnen wichtig, nicht aber für die RA-Betroffenen. Die Interviews ermöglichten es, die Antworten der RA-Betroffenen in den Fragebogen besser zu verstehen und erklärten die Unterschiede zu den Ergotherapeutinnen. RA-Betroffene erklärten, dass der erlebte Nutzen von Gelenkschutz und zunehmende Krankheitsakzeptanz ihre anfänglich wahrgenommenen Barrieren in eine positive Haltung gegenüber Gelenkschutz verändert hatten. Die Ergebnisse dieser Studie weisen darauf hin, dass die Betonung des Nutzens eine wichtige Kommunikationsstrategie in der Gelenkschutz Edukation sein könnte und die Identifizierung der individuell wichtigen Barrieren helfen könnte, die Gründe zu verstehen, warum RA-Betroffene Gelenkschutzmethoden anwenden oder nicht.

Kapitel 5 (Development and Psychometric Properties of a Joint Protection Self-Efficacy Scale (JP-SES) using Rasch analysis) präsentiert den Entwicklungs- und Validierungsprozess eines Fragebogens für Gelenkschutz-spezifische Selbstwirksamkeit. Selbstwirksamkeit gilt als einer der wichtigsten Faktoren zum Erwerben, Anwenden und Beibehalten eines (neuen) Verhaltens. Selbstwirksamkeit ist einerseits die wahrgenommene Fähigkeit (oder Zuversicht) einer Person, in verschiedensten Situationen das verlangte Verhalten anwenden zu können (Kompetenz-Erwartung) und 2) die Erwartung dieser Person, dass dieses Verhalten einen positiven Effekt hat (Ergebnis-Erwartung). Selbstwirksamkeit wird erworben durch direkte Erfahrung, stellvertretende Erwartung (durch Rollenmodelle), verbale Überzeugung und durch Re-Interpretation von körperlichen Signalen. Direkte Erfahrung ist viel wirkungsvoller als indirekte. Um das langfristige Ziel von Gelenkschutzverhalten als eine aktive Strategie zum Bewältigen von Alltagsaktivitäten und sozialen Rollen, z.B. in Familie oder Beruf, zu erreichen, sind psychoedukative Lehrmethoden nötig. In diesem Konzept sind Üben unter Supervision und zuhause, Zielsetzungen und Feedback, Beobachten und Austauschen mit Peers, d.h. anderen RA-Betroffenen, in Gruppen und verbale Überzegungen, Austausch und Diskussionen wichtige Strategien. Alle diese Methoden sind auch wichtige Ansätze um Selbstwirksamkeit zu erwerben. Für diesen therapeutischen Ansatz könnte eine spezifische Selbstwirksamkeits-Skala nützlich sein, um die Patienten in ihrer Zuversicht zu unterstützen, Gelenkschutzmethoden zu erwerben, in vielen Situation und auch langfristig einzusetzen.

Das Ziel dieser Studie war deshalb, eine Skala für Gelenkschutz-spezifische Selbstwirksamkeit bei RA-Betroffenen zu entwickeln (joint protection self-efficacy scale, JP-SES). Die Entwicklung des JP-SES umfasste die Bildung der Fragebogen-Items und die Überprüfung der Konstrukt-Validität (messen alle Items Selbstwirksamkeit) und der Reliabilität (wie zuverlässig ist die Skala). Insgesamt 46 Items aus wissenschaftlicher Literatur und Erfahrung von Ergotherapeutinnen und RA-Betroffenen wurden ausgewählt. Nach semi-strukturierten Interviews und Feldtests mit RA-Betroffenen wurde ein 26-Item Fragebogen konstruiert. Dieser wurde von rund 100 RA-Betroffenen ausgefüllt. Mit der Rasch-Analyse wurde die Konstrukt-Validität überprüft. Die Skala wurde daraufhin auf 13 ‚gültige' Items reduziert, d.h. solche, die wirklich Aussagen über Gelenkschutz-spezifische Selbstwirksamkeit machten. Diese 13-Items Skala wurde von einer weiteren Gruppe von rund 120 RA-Betroffenen ausgefüllt. Eine weitere Rasch-Analyse führte zur endgültigen 10-Item JP-SES, die von der gleichen Gruppe nochmals ausgefüllt wurde (Test-Retest). Die Konstruktvalidität wurde bestätigt, die Items hatten eine hohe interne Konsistenz mit einem alpha-Wert von 92% und die Skala eine Zuverlässigkeit von 79% bei Testwiederholung. Nach diesem schrittweise Entwicklungs- und Test-Prozedere stand nun eine gültige (valide) und zuverlässige (reliable) Skala für Gelenkschutz-spezifische Selbstwirksamkeit bei RA-Betroffenen zur Verfügung.

Kapitel 6: Enhancing Communication of Patient's Illness Experience Facilitates Therapeutic Process: Two Case Studies Using PRISM (Pictorial Representation of Illness and Self Measure) enthält zwei Fallstudien zur Anwendung des PRISM in der Ergotherapie. PRISM ist ein neues und interaktives spielerisches Instrument. Es bildet die Beziehung zwischen der Krankheit und anderen Lebensaspekten ab: a) die wahrgenommene Belastung durch die Krankheit; b) wichtige individuelle Lebensfelder, die als Resourcen wirken können. Beide Bereiche können für Motivation und Verhaltensänderungen wichtig sein.

Wenn die PRISM Aufgabe durchgeführt wird, dann wird der Person eine weisse A4-grosse Metallplatte gezeigt mit einem festen gelben Punkt (7cm Durchmesser) in der rechten unteren Ecke. Die Person soll sich vorstellen, dass die Metallplatte sein ‚aktuelles Leben' symbolisiert und der gelbe Punkt sein ‚Selbst'. Eine rote Scheibe (5cm Durchmesser) symbolisiert die 'Krankheit'. Die Person wird aufgefordert, die rote Scheibe dorthin zu legen, wo sie am besten das erlebte Leiden aufgrund der Krankheit darstellt. Das quantitative Mass ist die "Self-Illness Separation" (SIS), die Distanz zwischen den Zentren der Scheiben ‚Krankheit' und ‚Selbst' (Maximaldistanz = 27 cm). Eine kleinere Distanz bedeutet eine höhere Belastung aufgrund der Krankheit, d.h. einen grösseren Leidensdruck (siehe Figur 1a im Kapitel 7). Für die erweiterte PRISM+ Aufgabe, werden analog zur roten Krankheitsscheibe weitere farbige Scheiben verwendet. Diese repräsentieren mögliche Ressourcen für den Betroffenen, z.B. Freizeitaktivitäten, Familie/Freunde, Arbeit. Die „Self-Resource Separation" (SRS) muss anders interpretiert werden als die SIS: eine grössere Distanz bedeutet einen weniger positiven Einfluss der Resource, eine kleinere Distanz einen positiveren Einfluss (siehe Figur 1b im Kapitel 7). Im klinischen Alltag zeigte PRISM ein hohes therapeutisches Potential. Die Fallstudien

machten deutlich, dass die Anwendung von PRISM in der Ergotherapie einfach und wirkungsvoll ist. PRISM optimierte und beschleunigte den therapeutischen Prozess und förderte die Kommunikation zwischen Patienten und Ergotherapeutinnen über individuelle Krankheitsaspekte.

Kapitel 7 und 8 präsentieren die Resultate unserer randomisierten kontrollierten Studie. Diese hatte das Ziel, die kurz- und langfristigen Effekte von individueller, PRISM-basierter Gelenkschutz Edukation (PRISM-JP) mit konventioneller Gelenkschutz Edukation (C-JP) bei RA-Betroffenen zu vergleichen. Einschlusskritierien für Teilnehmende waren: Diagnose RA gemäss ACR (American College of Rheumatology) Kritierien; funktionelle Einschränkungen im Sinne von Schwierigkeiten und/oder Schmerzen bei Aktivitäten in Finger- und Handgelenken, welche Ergotherapie rechtfertigten; genügend Deutsch-Kenntnisse. Schwere Einschränkungen in Fingern, Händen und Schultern waren Ausschlussgründe, weil solche Einschränkungen die Anwendung von Gelenkschutzmethoden gemäss den anerkannnten Gelenkschutzprinzipien verunmöglichen können und allenfalls eigene Lösungen gefunden werden müssen.

Interessierten RA-Betroffenen wurde erklärt, dass es bei der Studie um die Untersuchung zweier unterschiedlicher Lehrmethoden in der Ergotherapie ginge. Hingegen wurde nicht gesagt, dass es um Gelenkschutz ging, um das Verhalten der Teilnehmenden nicht zu beeinflussen. Die Studie wurde in vier rheumatologischen Zentren der Deutschschweiz durchgeführt. Als Studienvorbereitung wurde ein Konsensmeeting mit den involvierten Ergotherapeutinnen abgehalten, um die Standard-Gelenkschutzedukation festzulegen. Die Gelenkschutzedukation in allen Institutionen und damit der Konsens über Inhalt und Art repräsentierten die typische ergotherapeutische Gelenkschutz-Praxis in der Schweiz. Beide Studieninterventionen, C-JP und PRISM-JP, bestanden aus vier 45-Minuten Einzeltherapie-Sitzungen innerhalb von drei Wochen und einer zusätzlichen ‚Auffrischungssitzung' zwei Monate später.

Die Teilnehmenden wurden zufällig zu PRSIM-JP oder C-JP zugelost (sogenannt ‚randomisiert'). C-JP bestand aus der standardisierten Gelenkschutz-Edukation. Die Inhalte und Lehrmethoden waren in einem kurzen Manual zusammengefasst: mündliche und schriftliche Informationen über RA und Gelenkschutzprinzipien; Zeigen und begleitetes Üben von Hand-Gelenkschutzmethoden, v.a. in Küchenaktivitäten; Zeigen von geeigneten Hilfsmitteln. Die Ergotherapeutinnen der C-JP waren frei, wie sie die Elemente der C-JP über die fünf Sitzungen verteilten.

Die PRISM-JP bestand ebenfalls aus der standardisierten Gelenkschutz-Edukation, aber sie war viel individualisierter und basierte auf den PRISM Aufgaben (PRISM und PRSIM+), der Sozialen Lerntheorie und dem Konzept des Selbstmanagement. Die Elemente der PRISM-JP in den einzelnen Sitzungen waren festgelegt. In der 1. Sitzung wurde die PRISM-Aufgabe eingesetzt. um die wahrgenommene Belastung durch die RA oder RA-bezogene Schmerzen, d.h. den Leidensdruck, zu erfassen und um individuelle Gelenkschutzziele festzulegen. Dieser Klientenzentrierte Ansatz half, individuell *bedeutsame* Aktivitäten zu wählen – im Gegensatz zur konventionellen Gelenkschutzedukation, wo häufig *zweckorientierte* Aktivitäten der Bereiche Haushalt oder Selbstversorgung

(Körperpflege, ankleiden) vorkommen. In der 2. Sitzung wurde die PRISM+ Aufgabe eingesetzt, um die wichtigste individuelle Resource zu finden. Die Patienten wurden aufgefordert, diese während des Therapieverlaufs speziell zu pflegen, z.B. Musik hören oder Musik machen, Kinobesuche oder Freunde treffen. Diese Recource sollte so gewählt werden, dass sie keinen Zusammenhang mit den krankheitsbezogenen Problemen und den Gelenkschutz-Aktivitäten hatte. Das Ziel dieser Recourcenaktivierung war es, den positiven Effekt der gewählten Aktivität zu verstärken und damit die Motivation der Person für die Therapie zu steigern. In den Sitzungen 3 und 4 wurde der positive Effekt der Resource evaluiert und gestärkt.

Gelenkschutzaktivitäten und –übungen wurden im Verlauf der PRISM-JP Edukation zunehmend komplexer: a) Selbstbeobachtung von Aktivitäten, die Schmerzen oder Schwierigkeiten verursachten, und des Handeinsatzes – b) eines oder mehrere Gelenkschutzprinzipien auswählen, um sie in den Aktivitäten, die in Sitzung 1 ausgewählt worden waren anzuwenden - c) Gelenkschutzmethoden anwenden in individuell ausgewählten komplexen Aktivitäten und d) Transfer zu weiteren, individuell wichtigen Aktivitäten. Hausaufgaben, Zielsetzungen und Tagebuchführung waren weitere wichtige Elemente der PRISM-JP.

Umfangreiche Beurteilungen des Therapieerfolgs (sogenannte Assessments) wurden vor Beginn, nach 3 Monaten (vor der 5. Sitzung) und nach 6 und 12 Monaten durchgeführt. Der primäre Endpunkt *Gelenkschutz-Verhalten* wurde mit dem videobasierten D-JPBA-S beurteilt. Um sicherzustellen, dass die teilnehmenden Patienten ihr normales Gelenkschutz-Verhalten zeigten, wurden sie nicht informiert über den wahren Grund der Videoaufnahmen und mit leichter Konversation wurden sie davon abgehalten, sich speziell auf den Einsatz ihrer Hände zu achten. Eine Ergotherapeutin beurteilte alle Videoaufnahmen und damit das Gelenkschutzverhalten der Teilnehmenden anhand des D-JPBA-S Manuals. Die Beurteilerin war blindiert, d.h. sie wusste nicht, welche Behandlung die Person erhalten hatte und zu welchem Messzeitpunkt die Aufnahme gemacht worden war. Eine Anzahl von funktionellen Untersuchungen und von krankheitsspezifischen und psychologischen Fragebogen evaluierten die sekundären Endpunkte.

Kapitel 7: Effectiveness of an individualized resource-oriented joint protection education in people with rheumatoid arthritis präsentiert die kurzfristigen Resultate nach 3 Monaten. Total 53 RA-Betroffene nahmen an der Studie teil. Beide Gruppen verbesserten ihr Gelenkschutzverhalten signifikant ($p<0.000$), unabhängig ob sie C-JP oder die PRISM-JP erhalten hatten. Allerdings wendete die PRISM-Gruppe signifikant mehr Gelenkschutzmethoden an ($p=0.008$). Die Teilnehmenden der PRISM Gruppe hatten auch mehr Arthritis Selbstwirksamkeit (ASES $p=0.015$) und mehr Gelenkschutz-spezifische Selbstwirksamkeit (JP-SES $p=0.047$). Analysen innnerhalb der PRISM-Gruppe zeigten, dass diese Teilnehmenden nach 3 Monaten weniger Handschmerzen hatten ($p<0.001$) und dass diejenigen am meisten profitierten, die zu Beginn keine Gelenkschutzmethoden angewendet hatten. Wir schlossen aus diesen Resultaten, dass der PRISM-basierte Ansatz die Verhaltensänderung hin zu mehr Gelenkschutzanwendung und deren pscho-

logischen Nutzen verstärken konnte was sich möglicherweise positiv auf die Motivation auswirkte.

Kapitel 8 (6 and 12 months' effects of individual joint protection education in people with rheumatoid arthritis: A randomized controlled trial) präsentiert die langfristigen Resultate nach 6 und 12 Monaten. Zu beiden Zeitpunkten hatten beide Gruppen signifikant besseres Gelenkschutzverhalten (D-JPBA-S, $p<0.000$) im Vergleich zur Baseline. Die PRISM-Gruppe wendete weiterhin signifikant mehr Gelenkschutzmethoden an als die Kontrollgruppe, sowohl nach 6 Monaten ($p=0.018$) als auch nach 12 Monaten ($p=0.038$). Gelenkschutz-spezifische Selbstwirksamkeit war nach 6 Monaten in beiden Gruppen signifikant besser (JP-SES $p=0.03$). Die Analyse innerhalb der PRISM Gruppe zeigte, dass diese Gruppe nach 12 Monaten signifikant mehr Gelenkschutz-spezifische Selbstwirksamkeit ($p=0.02$), bessere Hand-Greifkraft ($p=0.04$) und weniger wahrgenommene Krankheitsaktivität ($p=0.05$) hatte. Wir folgerten, dass, im Gegensatz zu Gelenkschutz Edukation in Gruppen, im Einzelsetting eine signifikante Verbesserung des Gelenkschutzverhalten möglich ist, unabhängig von den Lehrmethoden. Allerdings unterstützte die PRISM-basierte Gelenkschutzintervention das Lernen von und die Adhärenz an Gelenkschutzmethoden wirksamer. Die häufigere Anwendung von Gelenkschutz in der PRISM-Gruppe war assoziiert mit positiven Langzeit-Effekten in Handgreifkraft, Gelenkschutz-Selbstwirksamkeit und wahrgenommener Krankheitsaktivität.

Kapitel 9 schliesslich enthält die allgemeine Diskussion über verschiedene Aspekte dieser Thesis. Sie umfasst 3 Teile. Der erste Teil fasst zusammen und diskutiert Methodische Aspekte und die Gültigkeit der verschiedenen Studien.

Der zweite Teil schlägt Konsequenzen dieser Forschungsresultate für die klinische Praxis vor. Um Verhaltensänderungen zu ermöglichen, empfehlen wir die Anwendung von psychoedukativen Methoden, dazu gehört auch PRISM, im klinischen Alltag. Dies betrifft nicht nur Ergotherapie, sondern genauso Physiotherapie, medizinische und therapeutische Sprechstunden und psychologische Beratung.

Wir schlagen auch vor, den Begriff ‚Gelenkschutz' mit einem alternativen Begriff wie ‚Ergonomische Edukation' zu ersetzen. Unseres Erachtens ist dieser Begriff besser geeignet, das moderne Konzept von Gelenkschutz als einer Strategie hin zu aktivem Coping und Selbstmanagement zu vertreten. Der neue Begriff wäre für Health Professionals, überweisende Rheumatologen und RA-Betroffene auch weniger irreführend als der alte Begriff der ‚die Gelenke schützen' im Sinne von ‚weniger gebrauchen' impliziert.

Basierend auf unseren Resultaten und denjenigen von früheren Gelenkschutz-Studien, betonen wir die Notwendigkeit von klaren Implementierungsstrategien, damit die Ergebnisse auch wirklich in den klinischen Alltag einfliessen.

Der dritte und letzte Teil schliesst mit Ideen für zukünftige Forschung im Bereich Gelenkschutz Edukation und betont die Notwendigkeit von methodologisch einwandfreien Studien.

Samenvatting

Het thema van dit proefschrift is patiënteneducatie ter bevordering van gewrichtsbescherming bij patiënten met reumatoïde artritis (RA). Het proefschrift bestaat uit negen hoofdstukken: een inleiding, zeven publicaties en een discussie.

Hoofdstuk 1 geeft een algemene inleiding in het thema en beschrijft de theoretische achtergrond voor educatie ter bevordering van gewrichtsbescherming bij mensen met reumatoïde artritis. Musculoskelettale aandoeningen zijn de meest voorkomende oorzaak van chronische ziekten. RA is een chronische systematische ziekte met een grote impact op korte en lange termijn. RA komt bij 0,8 - 1% van de bevolking voor en treft vooral de beroepsbevolking, dat wil zeggen mensen die jonger dan 65 jaar. Ondanks het feit, dat slechts een gering percentage van de bevolking aangedaan is, zijn, vanwege de leeftijd waarop RA optreedt, de economische gevolgen aanzienlijk. Het beloop van de ziekte is moeilijk te voorspellen en kan intermitterend zijn of, wat meestal het geval is, langzaam voortschrijdend verlopen. Wanneer de ziekte actief is, gaat dit gepaard met symptomen zoals pijnlijke ontstekingen van gewrichten die het gewricht kunnen beschadigen en tot vervormingen kunnen leiden. De functie van aangedane gewrichten kan op den duur sterk beperkt worden. Als gevolg daarvan kan de patiënt in de dagelijkse activiteiten beperkt worden. Mogelijke consequenties zijn beperkingen van participatie aan sociale contacten met familieleden en vrienden, betaald en onbetaald werk en limitaties bij de uitvoering van activiteiten in de vrije tijd. Deze beperkingen kunnen de levenskwaliteit negatief beïnvloeden.

Het doel van de huidige medicamenteuze behandeling is het onderdrukken van de ontsteking en de beschadiging van de gewrichten. Op dit gebied werd gedurende de afgelopen 10-15 jaar grote vooruitgang geboekt. De medicamenteuze behandeling begint in een vroeg stadium en maakt deel uit van een intensieve medische begeleiding. Vaak worden combinaties van medicijnen gebruikt, daaronder medicijnen uit de groep der biologicals zoals anti-TNF en Rituximab. Deze medicijnen bestaan uit kunstmatige eiwitten en kunnen het verloop van ziekteprocessen zoals reumatoïde artritis gunstig beïnvloeden

Helaas reageren 1/3 van de patiënten met RA onvoldoende op deze medicijnen, en andere patiënten vertonen ernstige bijwerkingen en stoppen met de medicamenteuze behandeling. Bovendien zijn er ook patiënten die al voor de ontwikkeling van deze nieuwe medicijnen RA hebben en aan gewrichtsdestructies en artrose leiden. Daarom blijft een multidisciplinaire behandeling noodzakelijk. Fysio- en ergotherapie streven

naar het behoud of de verbetering van het functioneren, de zelfstandigheid en de levenskwaliteit.

Bij patiënten met RA die functionele beperkingen ervaren, nemen problemen aan de handen een belangrijke plaats in. Verbetering van het gebruik van de handen stond op de prioriteitenlijst van patiënten, na pijnreductie, op de tweede plaats. In 2001 noemden 41.6% van de patiënten met RA als belangrijkste doel de verbetering van de handfunctie. Daarom is patiënteneducatie ter bevordering van de gewrichtsbescherming nog steeds een belangrijke interventie.

Patiënteneducatie ter gewrichtsbescherming bevordert het zelfmanagement en daarmee een verbetering van de dagelijkse activiteiten en bevordering van de 'roluitvoering'. Patiënten leren alternatieve technieken voor het uitvoeren van dagelijkse activiteiten en hebben daardoor meer controle over het eigen functioneren. Dat heeft een positieve invloed heeft op het psychische welbevinden. Voor het bereiken van de doelen van de gewrichtsbescherming zijn psychologische en didactische educatieve strategieën nodig. Deze educatieve strategieën bevorderen gedragsverandering en zelfmanagement. In Zwitserland wordt patiënteneducatie ter bevordering van de gewrichtsbescherming vooral in een individuele behandelsetting toegepast. Meestal worden vooral kennis en vaardigheden bevorderd. Er is evidentie voor de effectiviteit van groepsbehandeling ter gewrichtsbescherming. Het is echter onduidelijk, of ook een individuele behandeling effectief is.

Hoofdstuk 2 (Gap between short- and long-term effects of patient education in rheumatoid arthritis patients) beschrijft een systematisch overzicht van gepubliceerd onderzoek. Bij het onderzoek gaat het om de effectiviteit van patiënteneducatie bij mensen met reumatoïde artritis (RA). Ik zocht publicaties die tussen 1980 en juli 2002 gepubliceerd werden in de internet databanken Medline, Psychlit, CINAHL en in de Cochrane library. Elf van de 63 aanvankelijk geïdentificeerde publicaties van gerandomiseerde gecontroleerde studies voldeden aan de criteria. Twee onderzoekers beoordeelden de kwaliteit van de onderzoeksmethodologie aan de hand van een in Maastricht en Amsterdam ontwikkelde lijst. Voor de analyse van de resultaten van de studies werden de criteria van de Cochrane Collaboration gebruikt. Zeven van de 11 studies voldeden aan het merendeel van de criteria en hadden een hoge kwaliteit. De vier andere studies hadden een lage kwaliteit. De mate van evidentie voor de effectiviteit van patiënteneducatie zijn aan de hand van de criteria van van Tulder et al. beoordeeld. Daarbij werd ook rekening gehouden met effectiviteit op korte en lange termijn. De verschillende studies over patiënteneducatie vertoonden een grote variatie in behandeling, duur van de interventie, uitkomstmaten en duur van de nacontrole. Twee centrale bevindingen van de systematische review waren: 1) het verschil in effect tussen educatieve en psycho-educatieve interventies, en 2) het verschil tussen effecten op korte en lange termijn. Alleen psycho-educatieve patiënteneducatie heeft een positief effect op korte termijn. Deze resultaten ondersteunen het belang van psycho-educatieve methoden bij de patiënteneducatie en voor strategieën voor gewrichtsbescherming die een gedragsverandering op lange termijn bevorderen. Het onderzoek van Hammond et al (1999)

toonde aan, dat een psycho-educatieve strategie effectiever is om het volgen van de adviezen op lange termijn door patiënten te verbeteren. Het lijkt er dus op, dat aan deze psycho-edcatieve methode de voorkeur gegeven moet worden in de klinische praktijk.

Hoofdstuk 3: (Development and validation of a German version of the Joint Protection Behaviour Assessment in patients with rheumatoid arthritis). Dit hoofdstuk beschrijft het proces van de validering van een meetinstrument om te meten in hoeverre patiënten actief gedrag voor gewrichtsbescherming toepassen. Eerdere studies over gewrichtsbescherming gebruikten daarvoor vragenlijsten die patiënten zelf invulden en registreerden ter verbetering van gewrichtsbescherming. Vragenlijsten die door de patiënten zelf ingevuld worden zijn onderhevig aan veranderende attitudes en meningen en geven daardoor een te positief beeld van de daadwerkelijke gewrichtsbescherming. Daarom ontwikkelden Hammond et al (1999) een gestandaardiseerd assessment (Joint Protection Behavioural Assessment, JPBA) waarbij ze video-opnamen maakten van patiënten die instant koffie en een kleine maaltijd bereidden. De JPBA is een belangrijke ontwikkeling omdat het een objectieve directe observatiemethode is. De JPBA is daarom uitermate geschikt voor de evaluatie van de effectiviteit van interventies ter bevordering van gewrichtsbescherming.

De korte Duitstalige versie van de JPBA (D-JPBA-S) werd bij patiënten met reumatoide artritis (RA) aan de Zwitserse culturele omstandigheden aangepast en gevalideerd. Dit proces heet ‘cross-cultural adaptation’. We keken daarbij naar het bereiden van instant koffie. We schreven een manual (testinstructie) en evalueerden de klinimetrische eigenschappen. Het manual werd ontwikkeld in een consensus proces met acht ergotherapeuten die als experts voor de beoordeling van gewrichtsbescherming beschouwd werden. We maakten video-opnamen van 24 patiënten met RA en 10 gezonde personen. De activiteit ‘bereiden van instant koffie’ werd in 10 deel-stappen ingedeeld en systematisch beoordeeld. Na drie maanden maakten we opnieuw opnamen en onderzochten of de activiteit op dezelfde wijze uitgevoerd werd.

De video-opnamen van 10 toevallig uitgekozen patiënten en 10 gezonde personen werden onafhankelijk van elkaar door 6 ergotherapeuten beoordeeld. Alle beoordelaars werden daarbij geïnstrueerd zich daarbij streng aan de instructies van het manual te houden. Met een zogenaamde Rasch analyse, , onderzochten we de validiteit en betrouwbaarheid van de test. Negen van de 10 deeltaken voldeden vanuit statistisch oogpunt aan de eisen. De D-JPBA-S, bestaande uit 9 valide deeltaken, had een goede betrouwbaarheid bij herhaalde beoordeling door dezelfde persoon en bij herhaalde beoordeling door twee verschillende personen. Daarom is de D-JPBA-S een valide en betrouwbaar instrument voor de beoordeling van gewrichtsbescherming bij Duitstalige patiënten met reumatoïde artritis.

Hoofdstuk 4: (Perceived benefits and barriers to joint protection among people with rheumatoid arthritis and occupational therapists). In een volgende stap onderzochten we bij patiënten met reumatoïde artritis (RA) en bij ergotherapeuten het waargenomen nut en de barrières voor het toepassen van gewrichtsbescherming. We gebruikten daarvoor zogenaamde 'mixed methods' of gemengde onderzoeksmethoden met vragenlijsten en interviews. De beslissing om technieken voor gewrichtsbescherming te gebruiken is afhankelijk van de afweging van de voor- en nadelen. Het afwegen van de barrières en de positieve aspecten neemt bij het veranderen van gedrag, en bij persisterende gedragsverandering, een centrale plaats in. De overtuigingen van health professionals ten opzichte van een bepaald gedrag beïnvloeden de mate waarin ze patiënten motiveren hun gedrag te veranderen.

De resultaten van de vragenlijsten toonden aan, dat zowel de ergotherapeuten als de patiënten gewrichtsbescherming ter bevordering van de lichamelijke gezondheid en de persoonlijke controle over de klachten belangrijk vinden. Daartegenover stond, dat ergotherapeuten verschillende barrières voor gewrichtscontrole identificeerden, onder andere 'een negatieve houding van andere personen', 'een negatieve invloed op andere personen' en dat 'gewrichtsbescherming tijd kost wat ten koste van andere activiteiten gaat'. Voor patiënten met RA speelden deze barrières geen rol. De interviews gaven meer inzicht in de achtergrond van de verschillende door patiënten met RA en ergotherapeuten beschreven barrières. Volgens patiënten met RA leidde de ervaring met RA en het ervaren nut van gewrichtsbescherming tot een afname van de aanvankelijk waargenomen barrières.

De resultaten van deze studie wijzen erop, dat het voor de acceptatie van gewrichtsbeschermings-strategieën door patiënten met RA waarschijnlijk belangrijk is om de patiënten op het nut te wijzen. Daarnaast kan het zinvol zijn dat ergotherapeuten bij de communicatie rekening houden met de individuele barrières van de patiënten.

Hoofdstuk 5: (Development and Psychometric Properties of a Joint Protection Self-Efficacy Scale (JP-SES) using Rasch analysis) beschrijft het process van de ontwikkeling en validering van een instrument voor de meting van de zelfwerkzaamheid met betrekking tot gewrichtsbescherming. Zelfwerkzaamheid wordt als een van de belangrijkste factoren voor succesvolle gedragsverandering beschouwd. Daarbij gaat het achtereenvolgens om het aanleren, toepassen en langdurig toepassen van nieuw gedrag. Zelfwerkzaamheid is sterk afhankelijk van twee aspecten. Een grote rol speelt de verwachting een opgave succesvol te kunnen uitvoeren (self-efficacy expectation). Het tweede aspect is de overtuiging dat dit gedrag een positief effect heeft (outcome expectation). Zelfwerkzaamheid wordt verkregen door eigen ervaring, positieve ervaringsberichten van andere personen (role modelling), overtuiging door andere personen en door bewust interpreteren van fysiologische signalen. Eigen ervaring is veel effectiever dan indirecte ervaring.

Het doel op lange termijn is, dat patiënten de gewrichtsbeschermings-strategieën als actieve copingstrategie ter verbetering van dagelijkse activiteiten regelmatig toepassen Om dit doel te bereiken is de toepassing van psycho-edukatieve methoden noodza-

kelijk. Belangrijke aspecten van deze benadering zijn het oefenen onder toezicht, de zelfstandige toepassing thuis, het formuleren van doelen, feedback over de mate waarin de doelen bereikt worden, uitwisseling van ervaring met andere patiënten (peergroups), discussie en overtuiging. De zojuist genoemde aspecten zijn de basis voor het leren van gewrichtsbeschermings-strategieën en het verbeteren van de zelfwerkzaamheid.

Voor de planning van het management kan het zinvol zijn een meetinstrument voor de zelfwerkzaamheid met betrekking tot gewrichtsbeschermings-strategieën te ontwikkelen. Met behulp van een dergelijk meetinstrument kan de aanvankelijke zelfwerkzaamheid bepaald worden en de behandeling doelgerichter op een verbetering afgestemd worden om uiteindelijk het doel van het aanleren en de blijvende toepassing van gewrichtsbeschermings-strategieën te bevorderen.

Daarom was het doel van deze studie om voor patiënten met RA een meetinstrument voor de zelfwerkzaamheid met betrekking tot gewrichtsbeschermings- strategieen te ontwikkelen (joint protection self-efficacy scale, JP-SES). De stappen van dit onderzoek waren achtereenvolgens het ontwikkelen van de items, de validering en de bepaling van de betrouwbaarheid. Op de basis van wetenschappelijke publicaties en interviews met ergotherapeuten en patiënten met RA ontwikkelden we 46 items. Na een eerste testfase en interviews met patiënten ontstond een vragenlijst met 26 items die in de praktijk getest werd. Met behulp van een zogenaamde Rasch analyse onderzochten we de zogenaamde constructvaliditeit en reduceerden het aantal items in een eerste stap tot 13, en uiteindelijk tot 10 items. De betrouwbaarheid van de JP-SES was goed, dat wil zeggen, dat de resultaten bij herhaalde meting nagenoeg hetzelfde zijn. De JP-SES is dus een valide en betrouwbaar instrument voor de meting van de zelfwerkzaamheid met betrekking tot gewrichtsbeschermings-strategieën bij patiënten met RA.

Hoofdstuk 6: Enhancing Communication of Patient's Illness Experience Facilitates Therapeutic Process: Two Case Studies Using PRISM (Pictorial Representation of Illness and Self Measure). Dit hoofdstuk beschrijft de resultaten van een onderzoek bij twee patiënten ter illustratie van de toepassing van PRISM, een nieuw interactief hulpmiddel voor de behandeling. Met PRISM wordt de relatie tussen de ziekte, RA, en andere aspecten van het leven van de patiënt, met symbolen 'in kaart gebracht'. Weergegeven worden a) de door de patiënt door de ziekte waargenomen last, en b) relevante persoonlijke hulpbronnen/mogelijkheden. Beide aspecten beïnvloeden in belangrijke mate de motivatie en gedragsverandering. Op een wit bord in A4 formaat bevindt zich op de hoek rechts onder een 7 cm grote gele schijf. De patiënt dient zich voor te stellen dat het A4 blad zijn of haar leven voorstelt, en de gele schijf haar eigen "persoon" (self). Daarna krijgt de patiënt een rode schijf van 5 cm doorsnee die de "ziekte" (illness) symboliseert en plaats deze zodanig dat de last van de ziekte op dit moment weergeven wordt. De afstand tussen de twee schijven "persoon" en "ziekte" in is de "Self-Illness Separation" (SIS, 0-27, zie figuur 1a in hoofdstuk 7). Een kleinere afstand wijst op een grotere negatieve invloed van de ziekte. Daarna worden schijven geplaatst die de "hulpbronnen" van de patiënten symboliseren, bijvoorbeeld "vrijetijds activiteiten",

"familie en vrienden" en "werk". De afstand tussen deze schijven en de persoon, de Self-Resource-Separation (SRS), wordt omgekeerd geïnterpreteerd. Een kleinere afstand wijst op een sterkere positieve invloed van de hulpbron (zie figuur 1b in hoofdstuk 7).

Naar aanleiding van positieve ervaringen met PRISM in de praktijk verwachtten we een grote therapeutische waarde van PRISM. Deze studie bij enkele patiënten toonde aan, dat het gebruik van PRISM eenvoudig en zeer waardevol is. PRISM optimaliseerde en versnelde het behandelingsproces en bevorderde de communicatie over de omgang met de ziekte tussen patiënt en therapeut.

Hoofdstuk 7 en 8 beschrijven de resultaten van een gerandomiseerde gecontroleerde studie (randomized controlled trial, RCT). Het doel van de studie was de vergelijking van het effect op korte en lange termijn van patiënteneducatie ter gewrichtsbescherming (joint protection, JP) met en zonder PRISM (PRISM-JP en conventional JP ofwel C-JP). Het onderzoek werd uitgevoerd bij patiënten met reumatoïde artritis (RA) en functionele beperkingen van de handen, dat wil zeggen pijn en moeilijkheden bij het uitvoeren van activiteiten. Deze beperkingen waren een indicatie voor ergotherapie. Goede Duitstalige communicatie was een verdere voorwaarde om aan de studie deel te nemen. Niet toegelaten werden patiënten met ernstige gewrichtsdeformiteiten aan de handen, ellebogen en schouders. De reden hiervoor was, dat deze patiënten moeite hebben met het toepassen van gewrichtsbeschermings-strategieën en andere interventies noodzakelijk zijn.

De patiënten werden over het doel van de studie geïnformeerd, die eruit bestond twee verschillende educatieve benaderingen in het kader van de ergotherapie te vergelijken, zonder erop te wijzen dat de focus op actieve gewrichtsbescherming lag. De studie werd in vier centra voor reumatologie doorgevoerd. Alle ergotherapeuten werden voor de studie in de gestandaardiseerde methoden van patiënteneducatie voor gewrichtsbescherming geïnstrueerd. Beide educatieve behandelingen, C-JP en PRISM-JP, werden in het kader van vier individuele behandelingen van 45 minuten gedurende drie weken aangeboden met een vijfde behandeling ter bevordering van de toepassing op lange termijn na twee maanden (booster sessie). De patiënten werden gerandomiseerd, dat wil zeggen door toeval aan een van de beide behandelingen toegewezen.

Bij de conventionele behandeling, C-JP, werden traditionele educatieve methoden gebruikt. Ter bevordering van de standaardisering werd de behandeling in een manual beschreven. Patiënten kregen mondelinge en schriftelijke informatie over RA en de principes van gewrichtsbescherming. De technieken van gewrichtsbescherming werden gedemonstreerd en geoefend, meestal bij activiteiten in de keuken. Verder instrueerden de ergotherapeuten patiënten omtrent het gebruik van hulpmiddelen. De ergotherapeuten waren vrij in de keuze van de verschillende elementen van de behandeling.

De behandeling met PRISM, PRISM-JP, bestond eveneens uit gestandaardiseerde patiënteneducatie, maar was meer aan de individuele behoefte van de patiënten aangepast. PRISM-JP ging uit van de PRISM taken (PRISM / PRISM+) en was gebaseerd op sociale leertheorieën en zelf managementtheorieën. De PRISM-JP methode werd gedurende de eerste en vierde behandeling toegepast. Bij de eerste behandeling werden de

impact van RA, de aan RA gerelateerde pijn, de individuele hulpbronnen van de patiënt en de doelen van de patiënteneducatie voor gewrichtsbescherming geïdentificeerd. Deze patiëntengerichte benaderingswijze bevorderde de identificatie van doelen en de keuze van activiteiten die voor de patiënt belangrijk zijn. Patiënteneducatie voor gewrichtsbescherming werd langzaam complexer, beginnend met de bewuste waarneming van het gebruik van de eigen handen bij activiteiten die pijn veroorzaken en met moeite uitgevoerd worden. In een volgende stap werden mogelijkheden voor gewrichtsbescherming voor de gekozen activiteiten uitgekozen en toegepast. Daarna werden mogelijkheden om deze principes in andere situaties toe te passen besproken.

Het doel van de volgende behandeling was de identificatie van de belangrijkste individuele ressource die de patiënt beter wilde benutten. Daarbij werd het accent aanvankelijk bewust gelegd op hulpbronnen die niet met de uitvoering van moeilijke taken in verband staan, zoals luisteren naar muziek, naar de bioscoop gaan of kennissen bezoeken. De reden voor deze keuze was de bevordering van de positieve invloed van de ressource op de daarbij gekozen activiteit, en de verbetering van de motivatie door deze positieve ervaring. Tijdens de derde en vierde behandeling werd deze positieve ervaring geëvalueerd en versterkt. Bij de verdere PRISM-JP behandeling speelden thuis oefenen, doelen formuleren en zelfobservatie een belangrijke rol.

Metingen werden uitgevoerd voor de behandeling, na drie maanden (voor de booster behandeling) en na 6 en 12 maanden. De primaire uitkomstmaat was het gedrag in verband met gewrichtsbescherming, gemeten met de Duitse versie van het Joint Protection Behaviour Assessment, D-JPBA-S. De patiënten werden niet geïnformeerd over het doel van de video-opnamen om te bevorderen dat de uitvoering van de taken zo representatief mogelijk is voor de uitvoering in het dagelijks leven. Gedurende de opnamen vond een ontspannen gesprek met de patiënt plaats om te verhinderen dat deze het gebruik van de handen bewust beïnvloedde. De video's werden volgens gestandaardiseerde criteria beoordeeld door een onafhankelijke ergotherapeute met ervaring op het gebied van RA. Deze ergotherapeute was geblindeerd, dat wil zeggen dat ze niet wist welke behandeling de patiënten gekregen hadden.

Hoofdstuk 7: Effectiveness of an individualized resource-oriented joint protection education in people with rheumatoid arthritis presenteert de resultaten van de gerandomisieerde gecontroleerde studie na 3 maanden. In het totaal werden 53 personen met RA in de studie opgenomen. In allebei de groepen verbeterde het gedrag in verband met gewrichtsbescherming, maar de verbetering in de PRISM-JP groep was statistisch significant groter. Het grootste nut ondervonden personen die gewrichtsbescherming tot dusverre niet toegepast hadden. De patiënten van de PRISM groep hadden, in vergelijking met de andere patiëntengroep, ook een grotere zelfwerkzaamheid, gemeten met de "arthritis self-efficacy scale" (ASES), en een betere zelfwerkzaamheid met betrekking tot gewrichtsbescherming (JP-SES). Bij de patiënten van de PRISM-JP groep nam de pijn in de handen gedurende de behandeling af.

De conclusie op basis van deze resultaten was daarom, dat de PRISM behandeling duidelijke positieve effecten heeft op het gedrag en de zelfwerkzaamheid met betrekking tot gewrichtsbescherming, en waarschijnlijk ook op de motivatie van de patiënten.

Hoofdstuk 8: 6 and 12 months' effects of individual joint protection education in people with rheumatoid arthritis: A randomized controlled trial. In dit hoofdstuk worden de resultaten op lange termijn, na 6 en 12 maanden, beschreven. Allebei de groepen vertoonden een statistisch significante verbetering van het gedrag met betrekking tot gewrichtsbescherming. De PRISM-JP groep had ook een significant betere zelfwerkzaamheid met betrekking tot gewrichtsbescherming, een grotere handkracht en geringere klachten in verband met de ziekte.

Op basis van deze resultaten concludeerden we dat een individuele behandeling, in tegenstelling to een groepsbehandeling, effectief is ter verbetering van gewrichtsbeschermend gedrag. Dit effect is onafhankelijk van de gebruikte methode. De PRISM-JP methode is effectiever zowel om het leren te bevorderen als ter bevordering van de adherence tot JP methods. De toepassing van specifieke methoden ter verbetering van gewrichtsbeschermend gedrag hing samen met een verbetering van de kracht in de hand, de zelfwerkzaamheid met betrekking tot gewrichtsbescherming en de klachten in verband met de ziekte.

Hoofdstuk 9 sluit dit proefschrift af met een algemene discussie en bestaat uit drie delen. Het eerste deel gaat over de onderzoekmethodologie en de validiteit of geldigheid van de verschillende studies in dit proefschrift. In het tweede deel van de discussie beschrijf ik de mogelijke implicaties van dit onderzoek voor de toekomstige zorg. Een eerste aanbeveling heeft betrekking op het algemeen gebruik van psychoeducatieve methoden en PRISM ter bevordering van gedragsverandering. Dit geldt niet alleen voor de ergotherapie, maar ook voor de fysiotherapie, medische consultaties en psychologische begeleiding. Verder stellen we voor, om het begrip "gewrichtsbescherming" te vervangen door "ergonomisch advies". Het eerste begrip is misleidend omdat het begrip "gewrichtsbescherming" suggereert, dat het zinvol is om gewrichten minder te gebruiken. . "Ergonomisch advies" is een breder begrip dat ook de aspecten zoals coping strategieën en zelfmanagement omvat. Op basis van de resultaten van ons onderzoek en de resultaten van andere studies bestaat een grote behoefte aan maatregelen ter bevordering van de implementatie van de resultaten in de praktijk.

De discussie wordt afgesloten met aanbevelingen voor toekomstig onderzoek op het gebied van de patiënteneducatie voor gewrichtsbescherming en gedragsverandering. Daarbij wordt met nadruk gewezen op het belang van onderzoek met een goede methodologische kwaliteit.

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About the Author
Publications

Curriculum Vitae

Karin Niedermann was born in Olten, Switzerland on the 15th of May, 1964. She is married to René Schneider and they have three children, Jan (1999), Mara (2000) and Annik (2003).

Karin Niedermann obtained her senior high school diploma (Matura, Typ B) at the Gymnasium in St. Gallen, Switzerland, and graduated as a physiotherapist in 1988 at the Physiotherapy School Schaffhausen, Switzerland. In 1993, she became head physiotherapist of the departments of Internal Medicine, Dermatology and Radio-Oncology of the University Hospital Zurich, Switzerland. She developed a special interest in the subject of patient education and led working groups for integrating patient education into daily clinical physiotherapy practice and for developing an education tool for physiotherapists to support patients in their physical activity.

Between 1997 and 2000 she studied ‚Public Health' at the Universities of Zurich, Bern and Basel, earning her Master degree (MPH). Subsequently she became a member of the novel Research Unit at the Institute of Physical Medicine (head Prof. Gerold Stucki and Mrs. Omega Huber) of the Rheumatology Department, University Hospital Zurich, where she worked on projects about quality management in physiotherapy and physical exercise in diabetic patients. She also conducted a systematic review about patient education in rheumatoid arthritis patients, which became the first step of her PhD.

Karin Niedermann and Omega Huber initiated and led the Physiotherapy Sciences Program, the first scientific training for physiotherapists in Switzerland, which was run successfully between 2002 and 2008 in collaboration with the department of Epidemiology of the Maastricht University. In September 2009, Karin Niedermann became head of the new MSc PT program at the Zurich University of Applied Sciences, Winterthur, Switzerland.

Karin Niedermann served as an active member in the Swiss Physiotherapy Association in various functions. Since 2006 she is a member of the European League Against Rheumatism Allied Health Professionals' (EULAR AHP) Scientific Committee and also of the editorial board of ‚physioscience' (Thieme), a journal promoting physiotherapy research in the German language.

List of Publications

Original papers in peer-reviewed journals

Dagfinrud H, Halvorsen S, Vollestad NK, Niedermann K, Kvien TK, Hagen KB. Exercise programs in trials for patients with ankylosing spondylitis: do they really have the potential for effectiveness? Submitted 2010

Köller B, Niedermann K, Klipstein A, Haugebolle J. The psychometric properties of the German version of the new Worker Role Interview. Conditionally accepted in Work (2010).

Niedermann K, de Bie R, Kubli R, Ciurea A, Steurer-Stey C, Villiger PM, Buchi S. Effectiveness of Individualized Ressource-oriented Joint Protection Education in People with Rheumatoid Arthritis. A Randomized Controlled Trial. In Press, J Pat Edu Couns (2010)

Niedermann K, Hammond A, Forster A, de Bie R. Perceived benefits and barriers of joint protection among people with rheumatoid arthritis and occupational therapists. A mixed method study. In Press, J Musculoskeletal Care (2010).

Niedermann K, Forster A, Ciurea A, Hammond A, Uebelhart D, de Bie R. Development and Psychometric Properties of a Joint Protection Self-Efficacy Scale (JP-SES) in People with Rheumatoid Arthritis. Accepted Scan J Occup Ther (2010)

Niedermann K, Buchi S, Ciurea A, Kubli R, Steurer-Stey C, Villiger PM, de Bie R. 6 and 12 months' effects of individual joint protection education in people with rheumatoid arthritis: A randomized controlled trial. Submitted (2009)

Krayenbuehl PA, Schmid C, Niedermann K, Schulthess G, Spinas, GA, Wiesli P. Effects of Pioglitazone versus Exercise on Insulin Release and Insulin Sensitivity in Patients with Type 2 Diabetes in a Placebo-Controlled Randomized Study. Submitted (2009)

Niedermann K, Forster A, Hammond A, Uebelhart D, de Bie R. Development and Validation of a German Version of the Joint Protection Behavior Assessment in People with Rheumatoid Arthritis. Arthritis Care Res. 2007;57(2):249-255

Lehmann R, Vocac A, Niedermann K, Agosti K, Spinas G. Loss of Abdominal Fat and Improvement of the Cardiovascular Risk Profile by Regular Moderate Exercise Training in Patients with NIDDM. Diabetologia. 1995;38(11):1313-9

Peer-reviewed systematic review

Niedermann K, Fransen J, Knols R, Uebelhart D. The Gap between Short- and Long-term Effects of Patient Education in RA Patients. A Systematic Review. Arthritis Care Res. 2004;51(3):388-98

Other publications

Niedermann, K. Mixed methods offer new ways in health professionals' research. EULAR HP NEWS. 2010 (1)

Niedermann, K.: Wie werden Forschungsresultate in die Praxis umgesetzt? Editorial. Physioscience 2009 (4), 141

Niedermann K. Diabetes mellitus Typ 2 und körperliche Aktivität. FISIOactive. 2009;1:14-18

Niedermann K: Der Weltphysiotherapiekongress in Vancouver Editorial. Physioscience. 2007(2), 45

Kool, J.; Niedermann, K.: Professionalisierung der Physiotherapie in der Schweiz. Editorial. Physioscience. 2006 (2), 45

De Bruin E, Niedermann K, Swanenburg J, Uebelhart D, Jungo D. Das Forschungsprofil der zukünftigen Fachhochschule Gesundheit- Ausbildungsstätten im internationalen Vergleich. FISIOactive. 2005,11;5-14

Niedermann K, Fransen J, Huber E, Uebelhart D, Steiner W. Einstellungen und Arbeitsweise von PhysiotherapeutInnen – Begleitevaluation zum Outcome-Projekt 2000-2001. FISIOactive. 2002,7;4-13.

Niedermann K., Steiner W., Fransen J., Huber E., Santos-Eggimann B. Evaluation der Akzeptanz und Praktikabilität des Qualex–Projektes. Physiotherapie. 2000;3:19-25.

Niedermann K., Maspoli Büchi L. Patient Education: Integration in der Physiotherapie. Physiotherapie. 1998;11:13-17.

Book chapters

Hammond A, Niedermann K: Patient Education and Self-Management. In: Dziedzic & Hammond (Eds.). Rheumatology: Evidence-Based Practice for Physiotherapists and Occupational Therapists. 1st edition 2010, p. 77-97. ISBN 978-0-443-06934-5, Edinburgh-London-New York–Oxford-Philadelphia-St.Louis-Sydney-Toronto. Churchill-Livingstone Elsevier.

Niedermann K, Forster A: Funktionsorientierte Therapien. In "Rheumatoide Arthritis - ein Handbuch für Betroffene", 2. Auflage 2009, Schweizerische Polyarthritiker-Vereinigung, Seiten 65-80. ISBN 978-3-033-02035-1

Niedermann K. Physio- und Ergotherapie. In: Forster A (Hrsg). Aktuelle Aspekte in der Therapie der rheumatoiden Arthritis. 1. Auflage 2008, S. 134-138. ISBN 978-3-89599-285-8. Bremen-London-Boston: Uni-Med Verlag AG.